Family caregivers' quality of life:

the case of schizophrenia and affective disorders
(A mixed method study)

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Abstract

Severe mental illnesses, such as schizophrenia and affective disorders, have a considerable impact on the lives of not only patients but also their caregivers. Discovering the quality of life and its contributing factors for family caregivers of patients with mental illnesses helps health-care professionals as well as the system to work better with family caregivers. Also, it helps the caregivers to cope with patients in an adaptive way. The study aimed to identify the burden and quality of life of caregivers, their specific needs and coping strategies. Also, it aimed to develop a new questionnaire to measure caregivers' quality of life.

This study applied a mixed-method approach with three exploratory, quantitative and supplementary phases. The qualitative exploratory phase of the study was conducted via semi-structured interviews with 45 caregivers of patients with schizophrenia and affective disorders. Data were analyzed through qualitative content analysis. The quantitative phase was designed to develop and validate a new instrument to measure caregivers' quality of life as well as to provide main questions of the interview for the supplementary phase of the study. The supplementary phase of the study was conducted by semi-structured interviews with 18 caregivers of patients with schizophrenia and affective disorders. Data were analyzed by grounded theory analysis.

Findings of the study identified main burdens that the caregivers endured; additionally, main factors which contributed to the quality of life were revealed by developing and validating a new questionnaire. Findings of the supplementary phase of the study identified the core concept of caregiving experience as well as its main categories. Also, it proposes different kinds of coping strategies that caregivers adopted. Furthermore, this phase shows the trajectory of caregiving experience and coping strategies in different phases of the illness.

The study provides some suggestions for the system, health-care professionals as well as caregivers in order to increase caregivers' quality of life and to lessen the intention to entrust patients to an institutional take care center.

Keywords

Affective disorders, Family caregiver, Mixed-method study, Quality of life, Schizophrenia

Zusammenfassung

Schwere psychische Erkrankungen wie Schizophrenie und affektive Störungen haben nicht nur einen erheblichen Einfluss auf das Leben der Patienten, sondern auch ihrer Bezugspersonen. Die Entdeckung der Lebensqualität und ihrer relevanten Faktoren für pflegende Angehörige von Patienten mit psychischen Erkrankungen hilft Gesundheitsfachkräften sowie dem System, besser mit pflegenden Angehörigen zusammenzuarbeiten. Außerdem hilft es den Pflegekräften, auf eine adaptive Weise mit Patienten umzugehen. Die Studie zielte darauf ab, die Belastung und Lebensqualität von Pflegekräften, ihre spezifischen Bedürfnisse und Bewältigungsstrategien zu identifizieren. Außerdem sollte ein neuer Fragebogen entwickelt werden, um die Lebensqualität der Pflegekräfte zu messen.

Diese Studie wendet einen Mixed-Method-Ansatz mit drei explorativen, quantitativen und ergänzenden Phasen an. Die qualitative explorative Phase der Studie wurde mittels halbstrukturierter Interviews mit 45 Betreuern von Patienten mit Schizophrenie und affektiven Störungen durchgeführt. Die Daten wurden durch qualitative Inhaltsanalyse untersucht. Die quantitative Phase diente der Entwicklung und Validierung eines neuen Instruments zur Messung der Lebensqualität von Pflegekräften sowie der Bereitstellung von Hauptfragen des Interviews für die zusätzliche Phase der Studie. Die Ergänzungsphase der Studie wurde in halbstrukturierten Interviews mit 18 Betreuern von Patienten mit Schizophrenie sowie affektiven Störungen durchgeführt. Die Daten wurden mittels Grounded-Theory-Analyse untersucht.

Die Ergebnisse der Studie ermittelten die Hauptbelastungen, denen die Pflegepersonen ausgesetzt waren. Darüber hinaus wurden durch die Entwicklung und Validierung eines neuen Fragebogens die wichtigsten Faktoren für die Lebensqualität aufgedeckt. Ergebnisse der Ergänzungsphase der Studie identifizierten das Kernkonzept der Pflegeerfahrung sowie deren Hauptkategorien. Außerdem werden verschiedene Arten von Bewältigungsstrategien vorgeschlagen, die die Pflegekräfte übernommen haben. Weiterhin zeigt diese Phase die Trajektorie von Pflegeerfahrung und Bewältigungsstrategien in verschiedenen Phasen der Erkrankung.

Die Studie bietet einige Vorschläge für das System, Fachkräfte im Gesundheitswesen sowie Pflegekräfte an, um die Lebensqualität der Pflegekräfte zu verbessern und die Absicht zu vermindern, Patienten einem institutionellen Pflegezentrum anzuvertrauen.

Schlagworte

Affektive Störungen, Familienpfleger, Mixed-method, Lebensqualität, Schizophrenia

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Table of Contents

Chapter 1: Introduction

1.1. Background

Severe mental illnesses, such as schizophrenia, bipolar disorder, and major depression disorder, are often devastating for both patients and their families (Rose, Mallinson, & Gerson, 2006). Schizophrenia is among the most disabling and economically one of the most cost-intensive medical disorders, ranked by the World Health Organization as one of the top ten illnesses contributing to the global burden of disease (Murray & Lopez, 1996). Bipolar disorder (BD) and major depressive disorder (MDD) are major causes of suffering for patients, but they also affect the function and wellbeing of patients' families and caregivers (Ogilvie, Morant, & Goodwin, 2005) as well as their dependency on public welfare (Chadda, 2014; Reinhard, Given, Petlick, & Bemis, 2008).

Schizophrenia is a severe form of mental illness that affects about 7 per 1,000 of the adult population, most of whom are in the age range of 15 to 35 years (age of incidence); it has long lasting consequences and probable risk of chronicity[1]. The World Health Organization (2010) estimated that globally about 29 million people have schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to the chronicity of this illness (Europe, 2010). Studies suggested that about 20% of people with schizophrenia show unremitting symptoms and increasing disability, and around 35% of them show a mixed pattern with varying degrees of remission and exacerbations of different lengths. It is a disabling, chronic psychiatric

[1] Schizophrenia can run a chronic course. Many patients with schizophrenia have a long duration of illness; they lack insight into their illness and have frequent readmissions and relapse. Some individuals with schizophrenia have impaired cognitive and social functioning and residual symptoms, and these could be a significant family concern (Chien & Chan, 2004).

disorder that imposes numerous challenges in its management and consequences. It imposes high costs on patients with respect to personal suffering, on caregiver due to a shift of burden from hospital to families and ultimately on society at large with regard to costs of frequent hospitalizations, the need for long-term psychosocial and economic support, and the lost productivity (Awad & Voruganti, 2008). With the advent of deinstitutionalization, more patients with schizophrenia are now being cared for in the community by their families. Studies showed that in western countries, about 25%–50% of people with schizophrenia stay with their families after being discharged from the hospital and depend on the assistance and care of their families. In Asian countries, the move toward deinstitutionalization is impeded by cultural and social factors, which is related to accepting people with mental illness as members of society. However, Asian studies show that about 70% of patients with schizophrenia live with their family. They depend on the family for care provision (S. W.-c. Chan, 2011).

Bipolar spectrum disorders including bipolar I and bipolar II[2] have a prevalence rate of 0.8% and 1.1%, respectively (Merikangas et al., 2007). However, recently Zimmerman et al. (2011) contended that current prevalence rates are underestimated due to diagnostic problems (Vella & Pai, 2012). The lifetime prevalence of bipolar spectrum disorders in the United States is 4.4% and it is the sixth leading cause of disability worldwide (Lee et al., 2011).

Mohammadi, et al. (2005) in an epidemiological survey in Iran showed that the prevalence of psychiatric disorders was 10.81% (see table 1). It was more common

[2] Bipolar I disorder is defined as having experienced one or more lifetime episodes of mania; usually episodes of depression exist. The severity and duration of episodes may result in hospitalization.
Bipolar II disorder is defined as having experiences of episodes of both *hypomania* and depression but no manic episodes. It may not lead to hospitalization (Akiskal & Pinto, 1999).

among females than males (14.34% vs. 7.34%, P < 0.001). The prevalence of anxiety and mood disorders were 8.35% and 4.29% respectively. The rampancy of psychotic disorders was 0.89%; for neuro-cognitive disorders it was 2.78% and for dissociative disorders it was 0.77%. Among mood disorders, major depressive disorder (2.98%) and among anxiety disorders, phobic disorder (2.05%) had the highest incidence. The prevalence of psychiatric disorders among divorced and separated individuals was 22.31%; among residents of urban areas it was 11.77%; and among illiterates, householders and unemployed they were 13.80%, 15.48% and 12.33%, respectively (Mohammadi et al., 2005a). Also, Sadeghirad, et al. (2010) in a systematic review and meta-analysis estimated the current overall prevalence of MDD was 4.1% (Sadeghirad et al., 2010).

Table1. The Prevalence of different types of psychiatric disorders by sex (N = 25180). Mohammadi, et al. (2005)

Type of psychiatric disorders	Males (n = 12660)		Females (n = 12520)		Total (n = 25180)	
	Number	(%)	Number	(%)	Number	(%)
Mood psychiatric disorders						
Major depressive disorder	201	1.59	549	4.38	750	2.98
Minor Depressive disorder	28	0.22	54	0.43	82	0.33
Bipolar mood disorder	23	0.18	15	0.12	38	0.96
Mood disorder with psychotic feature	3	0.02	2	0.02	5	0.02
Total	**255**	**2.01**	**620**	**4.95**	**875**	**4.29**
Psychotic disorders						
Schizophrenia	23	0.18	39	0.31	62	0.25
Schizoaffective	9	0.07	16	0.13	25	0.1
Short term psychotic disorder	6	0.05	5	0.04	11	0.04
Schizopherniform	4	0.03	2	0.02	6	0.02
Other psychotic disorders	43	0.34	78	0.62	121	0.48
Total	**85**	**0.67**	**140**	**1.12**	**225**	**0.89**
Anxiety disorders						
Panic disorder	100	0.79	274	2.19	374	1.49
Generalized anxiety disorder	93	0.73	243	1.94	336	1.33
Obsessive compulsive disorder	91	0.7	353	2.8	444	1.8
Agoraphobia	34	0.27	141	1.13	175	0.7
Phobic disorders	113	0.89	403	3.22	516	2.05
Post traumatic stress disorder	98	0.77	150	1.2	248	0.98
Total	**529**	**4.15**	**1564**	**12.48**	**2093**	**8.35**
The neuro-cognitive disorders						
Epilepsy	199	1.57	255	2.04	454	1.8
Mental retardation (Severe)	56	0.44	51	0.41	107	0.42
Dementia	65	0.51	75	0.6	140	0.56
Total	**320**	**2.52**	**381**	**3.05**	**701**	**2.78**
Dissociative and Somatization disorders						
Somatization Disorder	16	0.13	30	0.24	46	0.18
Dissociative Fugue	3	0.02	5	0.04	8	0.03
Dissociative Amnesia	65	0.51	61	0.49	126	0.5
Depersonalization Disorder	7	0.06	7	0.06	14	0.06
Total	**91**	**0.72**	**103**	**0.83**	**194**	**0.77**
Total	**1280**	**10.07**	**2808**	**22.43**	**4088**	**17.08**

1.2. Significance of the study

As a result of de-institutionalization[3] over the last 60 years, the majority of care for people with a serious mental illness, specifically schizophrenia spectrum disorders and bipolar disorders, now is provided by informal caregivers (Harvey et al., 2008). It is estimated that 50%–90% of people with chronic psychiatric illness live with their families or friends and informal caregivers provide an important service by reducing the need for formal care and burden upon healthcare systems (Gater et al., 2014). Because caregivers must fill the gap between deinstitutionalization and the shortage of community resources (Kwan, 2000), it is necessary to pay more attention to their burdens and difficulties and to examine effective means of support to, at least, avoid illness due to caregiver stress.

Unfortunately, care giving can have a detrimental impact upon the lives and well-being of caregivers (Vella & Pai, 2012). Care giving estimates continue to escalate, and, as the population ages, the number of people requiring care will subsequently increase. These estimates will no doubt have an unprecedented effect on economy. Notably, the economic impact of informal caregivers was estimated to be $350

[3] Deinstitutionalization can be described as a process whereby the mentally ill people no longer reside in psychiatric hospitals for long periods of time and hospitalization is replaced by lodging in smaller and less isolated community-based centers (Bachrach, 1993).
Lamb and Bachrach (2001) assert that deinstitutionalization generally consists of three component processes:
(1) the release of mentally ill people from psychiatric hospitals to alternative facilities in the community,
(2) the diversion of potential new admissions to alternative facilities, and
(3) the provision of special services for the care of mentally ill people who are not in state hospitals.
Deinstitutionalization movement initiated in the 1960s after publication of a report by Joint Commission on Mental Health, created by federal law to report to congress. The commission alarmed inhumane conditions in institutions and mentioned that long-term treatment in state institutions had detrimental effects on patients with mental illness and also costs of providing institutional care were high. Thus, the commission recommended major legislative and programmatic reforms aimed at preventing hospitalization, reducing lengths of hospital stays when unavoidable, and returning patients to communities with appropriate aftercare and rehabilitation. In 1963 President John F Kennedy, building on the recommendation of the Joint Commission on Mental Health, and partly because of his sister Rosemary's intellectual disability, enacted mental health legislation which acknowledged deinstitutionalization as a national policy. In addition, deinstitutionalization was also given impetus by what was at that time an emerging and thriving social concern for the civil rights of mentally ill people and a strong view that mental illness could be treated and in some instances even cured. The year 1965 also brought crucial developments in terms of the federal funding sources for community mental health services to help them meet the needs of a large pool of mentally ill people migrating from state hospital to community health centers (Molefi, 2009; Scull, 1980).

billion in 2006 (Hermanns & Mastel-Smith, 2012). The impact of caregiving on caregivers' quality of life (QoL) is important (Caqueo-Urízar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009; Martens & Addington, 2001). Caregivers' negative experiences may affect their ability to care for the patient, restrict their roles and activities, and increase their psychosomatic, anxious or depressive symptoms (Awad & Voruganti, 2008; Schulz & Beach, 1999). This is an important concern because the involvement of family caregivers is essential for the optimal treatment of patients by ensuring treatment compliance, continuity of care, and social support (Reine, Lancon, Di Tucci, Sapin, & Auquier, 2003; Velligan et al., 2009). Therefore, maintaining caregivers' well-being is an important issue, both for the caregivers themselves and, indirectly, for the patients' health.

Caregivers of individuals with mental disorders have received significant attention in the last few years. Most of this research has focused on the caregivers' burden (objective and subjective) (Bauer et al., 2011; Moller-Leimkuhler & Obermeier, 2008; Ogilvie et al., 2005; Ostacher et al., 2008), stress (Möller–Leimkühler, 2006), perceived stigma (González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007; Gonzalez et al., 2007; Perlick et al., 2007), depression (Perlick et al., 2007) and psychiatric symptoms (Steele, Maruyama, & Galynker, 2010). Moreover, even though many studies illustrate daily difficulties, burdens and quality of life of family members of people with schizophrenia and mood disorders (S. W.-c. Chan, 2011; Ogilvie et al., 2005; Pratima & Jena, 2011; Shah, Wadoo, & Latoo, 2010; Steele et al., 2010; Vella & Pai, 2012; Wei, 2008; Yusuf, Nuhu, & Akinbiyi, 2009), only few studies have focused on exploring quality of life (QoL) among caregivers of individuals with BD or MDD, in contrast with other diseases, such as schizophrenia (Caqueo-Urízar et al., 2009; Zendjidjian et al., 2012) and also there is a dearth of studies about caregiver quality of life in these three groups and comparison of them with each

other (Heru, Ryan, & Vlastos, 2004; Wong, Lam, Chan, & Chan, 2012; Zendjidjian et al., 2012).

1.3. Purpose of the study

The specific aims of the present study are:

- Identifying the burden and QoL of caregivers by means of a questionnaire developed in this study and by episodic narrative interviews;
- Identifying specific needs of informal caregivers and supports required from institutions and health-care professionals;
- Identifying helpful and detrimental coping strategies of families under analysis.

At the end of the study, some recommendations will be presented for health-care professionals, the system and caregivers.

1.4. Caregiving of mental illness in Iran: an overview of the situation

Iran is one of the largest countries in the Middle East region, with a population of more than 70 million people, with diverse ethnicities (Rezazadehkermani, 2008). Life expectancy is 71 years, and 5.2% of Iranians are older than 65 years. Most Iranians (more than 95%) are Muslims (Navab, Negarandeh, Peyrovi, & Navab, 2013). In Iran, an epidemiological survey of psychiatric disorders on 25,180 adults showed that the annual prevalence of psychotic disorders including schizophrenia was 0.089% (Mansouri et al., 2013b). Another study indicated that the prevalence of psychiatric disorders was 10.81%. It was more common among females than males (14.34% vs. 7.34%, $P < 0.001$). The prevalence of anxiety and mood disorders were 8.35% and 4.29%, respectively. The predominance of psychotic disorders was 0.89%; for neuro-cognitive disorders it was 2.78% and for dissociative disorders it was 0.77%. Among mood disorders, major depressive disorder (2.98%) and among anxiety disorders, phobic disorder (2.05%) had the highest rate. The mental health pattern in Iran is similar to that of western countries, but it seems that the prevalence of psychiatric disorders in Iran is lower than these countries (Mohammadi et al., 2005b). It is estimated that at least about 7 million of the Iranian population suffer from one or more of the psychiatric disorders. This points at the importance of the role of the psychiatric disorders in providing preventive and management programs in Iran (Mohammadi et al., 2005a). A systematic review and meta-analysis revealed a current prevalence of 4.1% for MDD in Iran, which is in a medium range compared with other countries. USA (6.6%) and Ukraine (8.3%) have higher rates and countries like china (2%) and Japan (2.9%) have lower predominance. Women were 1.95 (95% CI: 1.55-2.45) times more likely to have MDD. The current prevalence of MDD for urban inhabitants was not significantly different from rural inhabitants (Sadeghirad et al., 2010).

According to the findings of World Mental Health (WMH) Survey Initiative, among low and middle income countries, life time prevalence rates of MDD are 7.2%, 14.6%, 3.5% and 3.3% in Iraq, Ukraine, China and Nigeria, respectively. Among high-income countries, the reported rates for Spain, Japan and USA are 10.5%, 6.7% and 16.2%, respectively. Twelve-month prevalence of MDD has been reported to be 2% in China, 2.9% in Japan, 8.3% in Ukraine, 5.7% in New Zealand, 3.9% in Spain, 3.7% in Mexico and 1% in Nigeria (Sadeghirad et al., 2010).

1.5. Iranian culture with respect to family and health

In Iran religion plays an important role in family life (95% of Iranians are Muslim); family ties are more important than political or social alignments; filial duty is highly regarded; traditionally, fathers and sons manage outside relations for the family while women usually manage the household and there is great respect for elders and those in authority. As in many other cultures, it is believed that health is based on keeping the body elements in 'balance' and that certain kinds of lifestyles, treatments and external factors can influence health, with diet having a significant bearing on one's state. Of particular importance is the notion of 'hot' and 'cold' which does not imply temperature, but is elemental in nature. From the Iranian Traditional Medicine point of view, temperament is a basic concept that helps the maintenance of health and treatment of disease (Farsani et al., 2014). Excess of either state can cause related illnesses, which can be treated through the use of the opposite foods to achieve balance. Individuals are hot, cold or neutral in nature.

In terms of spiritual/religious views, some people believe in God's will (tagdir) and in punishment from God for committed sins. This believes are less subscribed by the younger generations. Evil spirits known as 'Jinn' in Islam can cause some illnesses, (often associated with mental health problems), and 'Zar' spirit possession is seen as a cause of poor mental health. Some individuals have 'evil eye' which can put a curse on others by looking at them. 'Esfand' is a seed burned to ward off the evil eye and possibly bad spirits and wild rue seeds are burned to remove the effect of evil eye. A 'doa nevis' (writer of amulets and benedictions) inscribe verses of the Koran or prayers which clients attach to themselves as protections against spirits. There is a great variance in adherence to traditional practices amongst Iranians. Younger Iranians are generally familiar with scientific medicine and health systems and use traditional practices less frequently than older generations. Tentative diagnoses, reliance on diagnostic tests and not prescribing medicines can be interpreted as signs of incompetence in the common medical practices in Iran. Severe mental disturbance (distress or 'craziness/madness') is stigmatized and committing suicide would be highly denounced as this is forbidden in Quran (Jackson, 2006; Kemp & Rasbridge, 2004; Perumal, 2010). Iranian families see mental illness from the perspective of determinism i.e. as predestination and fate. Culturally in Iran, families are very reluctant to disclose mental illness of female relatives (Koolaee & Etemadi, 2009).

Altruism and strong family ties are two basic characteristics of Iranian culture, which are also magnified by social expectations. Iranians are highly committed to maintaining close relationships with their family and providing care for an ill family member. Moreover, the elderly are highly respected because of their supportive role, authority and credibility among families. Accordingly, caring for older family members is highly valued and socially praised in the Iranian culture. In this context,

any judgment about an individual can affect not only that person but also his/her family members. Consequently, stigma can negatively affect all aspects of a family's social life (Navab et al., 2013). Iranian families are characterized by their intimate interpersonal relationships and a great deal of interactions among family members. Therefore, illness of one family member results in a substantial burden on the whole family. In addition, Iranian families report a low level of formal support services as compared with their Western peers. Currently, there is no community mental health center devoted to provide further care for patients with schizophrenia in Iran. Patients mainly refer to psychiatrists or Psychiatric centers or primary healthcare centers that do not clearly address the specific needs of each family. When behavioral problems become unbearable for the family, the psychiatric centers are contacted first but unfortunately, they are not easily accessible to the patients and their caregivers, especially for those who live in rural area. Physical accessibility such as improper transport to the mental health centers, long distance to the facilities, long intervals between visits, and waiting time for the consultations are the main problems (Forouzan et al., 2013). Moreover, since mental illness is considered as a taboo in this cultural setting and many families are not aware of the needs and illness of their patients, they experience a great deal of burden. Also, neither the patients nor their families do receive routine non-pharmaceutical treatments such as family interventions. Moreover, there is a lack of trained professionals to perform such interventions (Sharif, Shaygan, & Mani, 2012). In Iranian households, girls or women are responsible for taking care of children, patients, elderly and disabled people in the family as a part of their daily household chores (Ali Navidian, Fatihe Kermansaravi, & Shahindokht N Rigi, 2012a). Thus, they endure more burden than other family members.

A study conducted in Iran revealed that, in spite of the burden that is imposed on families, most families are willing to take care of their loved ones at home. Their most pressing needs are stated to be accessibility to hospital beds at times of relapse and provision of rehabilitation and educational services. There is a shortage of psychiatric beds but resources such as family support are available, so there is the possibility of developing innovative, less expensive and more efficacious community services for the mental health system of the country (Malakouti et al., 2009). Iran lacks sufficient health services for psychiatric hospitalization of patients and has inadequate community-based facilities, and outreach services are a critical problem. These have imposed the burden of care on families. A recent study showed that Iranian caregivers experience a significant amount of problem in their mental health status. A study showed that Iranian families are willing to take care of their patient members at home; meanwhile they have reported their needs for available hospital beds at the time of referral and urgent requirements for rehabilitation and educational programs. In recent years, there has been a gradually increasing trend of psychiatric hospitalization of patients through family referrals in Iran (Mansouri et al., 2013a). An explanation is that there is a deficiency of community psychiatry. Although there is no domestic scientific research, modern working-time schemes and lack of sufficient lodging-room may be proposed as two more reasons for this trend. Thus, pressures to entrust ill family members into hospital care might have been grown. Community psychiatry movement was developed during the early 1960s in the world. In Iran -pioneer of this movement in the region- the change from traditional hospital psychiatric services towards community care was developed during 1976 to 1979 by establishing a center for new community-oriented psychiatric training, by decentralizing psychiatric services in a few small general hospitals, and also administering a pilot project of a few comprehensive community

mental health centers in the city of Tehran. This revolution in psychiatric service delivery increased and developed nationwide by planning national integration of Iranian mental health with the primary health care program in the Ministry of Health and Medical Education with support of WHO (EMRO), in 1985. Second generation of young psychiatrists did not conform to new changes in community-based psychiatric training. So at this time, mental hospitals were surged with mental and addicted patients with no community care and facilities. Challenges and barriers to promote and continue community psychiatry trainings in Iran were as follow:

1- Shortage of cooperation and coordination at national, local, and departmental levels;

2- Lack of standard methods and tools for evaluation of the community field trainings;

3- Shortage of time to learn more about the variety of problems in the community.

4- Deficiency of community care skills in residency training before 3rd or 4th year of training.

5- Lack of motivation and attraction for health personnel in the field as well as for trainers' supervisors.

6- Absence of expert trainers for working in the community field (Abolhasanzadeh, Beyraghi, & Mohajer; Afshar, 2011).

Insufficient coverage of health insurance, especially in the private medical centers, and high costs of treatment even at the governmental hospitals were also major problems for both patients and their families. Despite having health insurance, the

major portion of patients' treatment costs had to be paid by the family. In Iran, most of the patients are referred to governmental clinics and hospitals where there is a lot of workload; consequently, the healthcare team has little time to address family caregivers' informational needs. Also, nurses often emphasize the secondary level of preventative care, particularly for patients in hospitals, rather than primary level prevention. There is no educative system for family caregivers and they have little opportunity to receive guidance for delivering safety care to their patients. The provision of adequate care-related knowledge for the family caregivers could be a principal step toward reducing caregivers' burden (Bahrami, Etemadifar, Shahriari, & Khosravi Farsani, 2014).

Based on the Iranian culture, when there is a chronic illness, at first, there is a high level of family support, but the support reduces over time and both patients and their families lose hope for the future. One explanation is that the monthly family income is not sufficient to meet the high costs of patients' treatment because of high economical inflation rate and economic sanctions. Thus, providing more formal support and resources for them may reduce their burden, patients' readmission, costs of treatment, and disturbances of patients' treatment process (Bahrami et al., 2014).

In Iran, families have traditionally been partners in the care of patients, and despite difficulties imposed on families for the care of patients with schizophrenia, they prefer to take care of their patients at home rather than using long-term care facilities. There is no information about the family burden of schizophrenia in Iran. Considering different ethnicities and cultural attitudes and beliefs in Iran and Islamic and traditional nature of families which make it different from other countries, there is a need to assess the effects as well as implications of psycho-educational

programs on family burden of Iranian patients with schizophrenia in acute phase of disease (Fallahi Khoshknab, Sheikhona, Rahgouy, Rahgozar, & Sodagari, 2014).

1.6. Mental health services in Iran

Health care system in Iran is based on three columns: public-governmental system, private part, and NGOs (Mehrdad, 2009). It has experienced several reforms in the past three decades. The most important reform was the formation of the National Health Network in 1983, which aimed to reduce inequities and expand coverage and access to health care in deprived areas (Heshmati & Joulaei, 2016). Mental health services have been combined into a hierarchical, pyramid-like, National Health Network since 1986. At the base of the pyramid, some educated health workers identify, refer, and follow mental health cases to the urban health center where General Practitioners (GPs) manage psychiatric patients. All cities in Iran have urban health centers each of which aids a definite population of around 12,000 people. According to the mental health program, GPs are selected to screen under-covered individuals constantly and to recognize patients who suffer mental disorders and who need referral to psychiatric clinics. District health centers afford more specialized mental health services by a trained GP and on some cases, a psychiatrist. The district health center admits mental health referrals from urban and rural health centers, but sometimes refers difficult cases to the provincial health center, of which there are 40 in 30 provinces. Provincial health centers are under the administration of medical universities. Medical universities are liable for both health services and medical education. The mental health parts in these services are staffed by one psychiatrist and one psychologist who are liable for the technical, organizational, and administrative management of services on the margin. Medical universities provide mental health services to patients referred from district health centers,

commonly in psychiatric hospitals or in the psychiatry wards of general hospitals. In provincial capitals, one or more comprehensive hospitals afford the highest level of outpatient and inpatient mental health care. In Tehran, a comprehensive hospital in each partition of the city (North, South, East, West, and Central) proposing both inpatient and outpatient mental health services. These hospitals have referrals from both different partitions of the city and even other cities in the country. Referrals to these hospitals can be through primary health care system or directly at patients' own initiative. In Tehran, several NGOs also afford day-care and rehabilitation services to mentally ill patients. All of them work under the administration of a medical university. The service expenses for both public and private services are covered by social health insurance (Forouzan et al., 2013; Mohit, 2000). Despite the profits of this hierarchical health care system mainly for deprived areas and increase in health indicators, there is still a poor referral system because of differences in policy administration, information flow, structural association, and steadiness of care at various levels of health care. In recent years there was Health Sector Evolution Plan in health care system of Iran. The main purposes of this plan are to reduce health costs for patients, improve hospital organization and quality of services and afford equal access to inpatient care (Moradi-Lakeh & Vosoogh-Moghaddam, 2015). This plan was welcomed firstly because it caused a reduction in health costs of the patients and increased the income of health providers but some challenges such as heavy financial burden on government, neglect of primary health care, ineffective payment methods, rare financial sources, unequal distribution of specialists, and disregard of outpatients in public sectors and patients in private hospitals may have negative impact on it in the future (Heshmati & Joulaei, 2016).

Chapter 2: Literature review

2.1. Introduction

In this chapter, based on the aim of the study, the related literature in Iran and other countries will be reviewed and the main concepts of the study will be defined. The literature will focus on family caregivers of schizophrenia and affective disorders in terms of burdens they bear and their quality of life and influential factors with regard to the socio- demographic variables.

The literature review will be started by defining and explaining main concepts of the current study, including family caregiver, schizophrenia, affective disorders and quality of life. Then, different studies related to caregiving experience with respect to quality of life, burdens affecting it, contributing socio-demographic variables and coping strategies will be discussed.

2.2. Family caregiver

Several definitions for "caregiving" and "family caregiver" have been proposed in literature. The first recorded use of the term "caregiving" was in 1966. Etymologically, the word "care" comes from the old English term "wicim," which means "mental suffering, mourning, sorrow, or trouble". "Give" is also old English, from "ȝeo-, ȝiofan, ȝiaban," and means "to bestow gratuitously". Caregiving, as the integration of the two origin meanings, is the action/process of helping those who are suffering (Hermanns & Mastel-Smith, 2012). Sociologists hardly define caregivers as unpaid workers such as family members, friends, and neighbors as well as individuals associated with religious institutions (Drentea, 2007). The Merriam Webster dictionary (2010) defines caregiver as "a person who provides direct care,

as for children, elderly people, or the chronically ill". Drentea (2007) refers to caregiving as "the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological or developmental needs". According to the results of a qualitative study, caregiving is the process of helping another person who is unable to do things for himself/herself in a "holistic" (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain characteristic traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient (Hermanns & Mastel-Smith, 2012). In our study, the sociological concept of family caregiving offered by Drentea (2007) is referred to.

2.3. Schizophrenia

Schizophrenia is considered one of the most devastating disorders. Mostly, schizophrenia includes a set of disorders with various etiologies. It includes patients with a variety of response to treatment, clinical performances, and courses of illness. Schizophrenia symptoms comprise variations in feeling, insight, thinking, and behavior. Although the expression of these symptoms is different amongst the patients, the effect of the illness is always severe and is usually long term. Schizophrenia usually initiates before age 25 years and continues throughout life. It affects people of all social classes. Both patients and their families often experience poor care and social isolation because of lack of sufficient knowledge about the illness. Schizophrenia as one of the most prevailing severe mental illnesses has an ambiguous nature and its essential nature remains to be seen. Thus, it is sometimes mentioned to as a syndrome, as the set of schizophrenias, or as the schizophrenia spectrum. Because schizophrenia initiates at the first stage of life, it causes significant and long-term impairments. Consequently, it makes heavy demands for

hospitalization; and needs constant clinical care, rehabilitation, and support services. (Sadock & Sadock, 2011).

2.4. Affective disorders

Major depression disorder (MDD) and bipolar mood disorder (BMD) are two main groups of mental disorder known as affective or mood disorders. Mood can be defined as a prevalent and constant emotion or feeling tone that impact a person's behavior and colors his or her insight of existence.

A range of words such as depressed, sad, discontent, melancholic, distressed, delighted, excited, manic, happy, and so on, are used to describe the mood. Some can be detected by the clinician, for example, an unhappy face, and others can be felt only by the patient such as hopelessness. Mood can be fluctuating quickly between extremes, for example laughing loudly and widely one moment, upset and hopeless the next. Mood disorders have also some other signs and symptoms such as changes in activity level, cognitive skills, speech, and somatic functions like sleep, appetite, sexual drive, and so on. These disorders may lead to impaired interactive, social, and work-related functioning.

Mood disorders consider on a continuum with normal variations in mood. Individuals with mood disorders often report an indescribable and distinct quality of their pathological state. Patients with only major depressive episodes are named major depressive disorder (MDD) or unipolar depression. Patients with both manic and depressive episodes or patients with manic episodes alone are named bipolar mood disorder (BMD). The term “unipolar mania” and “pure mania” are sometimes used for individuals with bipolar mood disorder without depressive episodes.

During the past 20 years, major depression disorder and bipolar disorder has been considered as the two separate disorders. Recently, the possibility that BMD is a kind of more severe expression of MDD has been investigated. However, many patients diagnosed with MDD disclosed past undetected episodes of manic or hypomanic behaviors. Numerous specialists see significant continuity between recurrent depressive and bipolar disorders. This has resulted in an extensive argument about the bipolar spectrum, which incorporates classic bipolar disorder, bipolar Π, and recurrent depressions (Sadock & Sadock, 2011).

2.5. Quality of life

Although over the past five decades a lot of studies have been conducted on the quality of life and factors contributing to it, there is no consensus on the definition of "quality of life". As many studies have dealt with this subject, a wide variety of definitions for quality of life has been rendered. Variation in definition of quality of life stems from heterogeneity of theories or conceptual frameworks. This variation leads to a diversity of quality of life measurements. Rosenberg (1995) stated that determining construct validity for quality of life is difficult because of a lack of clarity for the theoretical states of this concept.

Quality of life includes two modes named subjective quality of life and objective quality of life. The subjective component is directly associated with life experiences (Murphy & Murphy 2006), indicated by individual's satisfaction with his/her present life situations and evaluated subjectively. The objective dimension of quality of life is assessed by individual's health, social and material well-being and is often measured by objective evaluation (Yasien, Alvi, & Moghal, 2013).

There are various definitions of Quality of Life (QoL). Ferrans and Power (1996) defined quality of life as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her". Rosemarie Parse (1994) considered quality of life as: ''the incarnation of lived experiences as the indivisible human's view on living moment to moment as the changing patterns of shifting perspectives weave the fabric of life through the human-universe interconnectedness". Leininger defined the quality of life as "culturally constituted care values, meanings, symbolic forms, and patterns of collective human expressions that are powerful forces to guide, maintain, and promote the health and wellbeing of particular culture". The World Health Organization's Quality of Life (WHOQOL) group (1993) defines quality of life as "an individual's perception of life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (Kwan, 2000). The emphasis is on the individual's perception of life which indicates a subjective judgment made by the participant. It is a broad ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment. This definition highlights the view that quality of life is subjective; it includes both positive and negative facets of life and is multi-dimensional (Basu, 2004). The definition of QoL often depends on the area of one's life which is being assessed, with the term "Health-Related Quality of Life" (HRQoL) being applied to the impact of illnesses or treatments on the lives of patients or those around them (Golics, 2013).

Although there is no consensus on the definition of QoL, considerable agreement has been reached on some central characteristics. First, QoL is subjective in nature and it is oriented toward the individual experience; moreover, the final authority or

assessor of QoL is the individual who lives that life. Second, QoL is a multidimensional concept that has physical, psychological, and societal facets that vary according to the conceptual, pragmatic, and empirical purposes of the particular group developing the assessment instrument. Third, QoL is a dynamic concept that can change from day to day and is characterized by its individuality; each person perceives his or her QoL as different from that of others (Alshowkan, Curtis, & White, 2012).

Based on the above review, the closest definition to this author's view is the definition of the world health Organization's Quality of Life (WHOQOL) because it presents a subjective perception of life which consists of multiple dimensions including physical, psychological, social and environment dimensions.

2.6. Study rationale for development and validation of new questionnaire

Mental illnesses, especially schizophrenia and affective disorders can have detrimental impacts on both patients and caregivers (Vella & Pai, 2012). Caregivers of individuals with mental illness experience significant burdens including emotional, physical, financial and psychosocial burdens and consequently, a reduced quality of life (QoL). Caregivers' reduced QoL may affect their ability to care for the patients, restrict their roles and activities and increase their psychosomatic, anxious, or depressive symptoms and subsequently the continuity of care and optimal treatment of patients can be affected (Chan & Yu, 2004; Martire et al., 2009; Richieri et al., 2011; von Kardorff, Soltaninejad, Kamali, & Eslami Shahrbabaki, 2015; Wong, Lam, Chan, & Chan, 2012). About 50%–90% of patients with chronic psychiatric diseases live with their families or friends, thus caregivers are key-actors in the provision of health care, treatment adherence by patients and development and evaluation of health programs and policies (Caqueo-Urízar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009; Gater et al., 2014; Richieri et al., 2011).

Several researches have focused on burden, coping strategies, quality of life and other specific issues about caregivers of mental patients in the last few years (Chan & Yu, 2004; Martire et al., 2009; Richieri et al., 2011; von Kardorff et al., 2015; Wong et al., 2012). Some studies had focused on stigmatization of families with mentally ill patients (Angermeyer, Schulze, & Dietrich, 2003) and only one study has been done to develop a special questionnaire for assessing the quality of life of caregivers' of schizophrenics (Richieri et al., 2011). It does not include a wide sample of caregivers of patients with mental illnesses such as affective disorders as well as different relatives such as spouses, siblings and children of the patients. Moreover, the current study has been done in a different cultural context. Thus, it may test the

strengths and weaknesses of the previous questionnaire as the authors used most items of that questionnaire in the initial raw questionnaire.

To the best of our knowledge, no QoL measurement scale has already been specifically developed for caregivers of both individuals with schizophrenia and affective disorders (Caqueo-Urízar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009). There are some generic questionnaires like WHO-QoL BREF or SF36 to measure QoL in general population including healthy and unhealthy peoples (Usefy et al., 2010). These measures were not designed to be used to assess the impact of illness on the family caregivers and specific burdens that they experience. Thus, they cannot measure specific dimensions of caregivers' QoL that are affected by the specific disease.

Exploring the impact of specific disease on the family caregivers will allow comparisons between different diseases in terms of the impact on family members. Also, aspects of family caregivers' lives which are affected will be identified, and a more distinct idea of dimensions where more support is required will be given. The new measure might be an improvement over existing measures through both measuring QoL of a large group of family caregivers (schizophrenia and affective disorders) and providing a measure for a different cultural and social context.

Developing an instrument to measure caregiver QoL of mental illnesses could be useful in detection of caregiver quality of life state and gives hints for improving health of patients and their caregivers. In other word, it helps caregivers to care and manage their ill relatives better, and managers to plan for better quality of life for caregivers. The purpose of this study is to develop and validate a new and specific instrument to measure QoL of caregivers of schizophrenia and affective disorders.

2.7. Caregiving experience (quality of life, burdens and coping strategies)

Despite the large number of studies about quality of life in family caregivers of mental disorders, there are contradictory results especially about caregivers of affective disorders. According to a study by Xavier Zendjidjian et al. (2012), caregivers of affective disorders reported lower QoL levels in mental dimension than in the physical. There was no statistically significant difference in SF 36 dimension scores between caregivers of individuals with Bipolar Disorder (BD) and Major Depressive Disorder (MDD). On the contrary, mental dimensions were statistically lower for caregivers of individuals with MDD than for caregivers of individuals with BD. Also, caregivers of individuals with BD and MDD reported higher QoL dimension scores than caregivers of individuals with schizophrenia. Caregivers of individuals with BD reported higher physical health than caregivers of individuals with schizophrenia, whereas caregivers of individuals with MDD reported higher mental health. In the multivariate analysis it was showed that there is no relationship between various parameters and physical health, except for age. Older caregivers reported lower QoL levels. In contrast, several parameters were significantly associated with lower mental health: gender, relationship with the patient, living in the same home and type of illness. Women, parents/family or spouse, caregivers living in the same home and caregivers of individuals with MDD reported altered QoL levels (Zendjidjian et al., 2012).

According to Moller-Leimkuhler (2006) caregivers of individuals with mood disorders reported higher QoL levels than caregivers of schizophrenics. Interestingly, the differences between caregivers of individuals with BD and individuals with schizophrenia is related to mental and psychological dimensions while the differences between caregivers of individuals with MDD and schizophrenia is only

related to physical dimensions. These findings confirm the necessity of a multidimensional approach in identifying the most-impaired domain to improve programs for caregivers (Möller–Leimkühler, 2006). Some studies have found that the relationship between the caregiver and the patient (parent/family or spouse) and living together in the same home were associated with lower QoL levels, whereas QoL was not significantly associated with clinical characteristics such as illness duration. These findings suggest that the proximity of the caregiver to the patient, rather than the severity of the patient's illness, has a greater impact on the caregiver's experience (Zendjidjian et al., 2012). Families of patients with affective disorders experience high levels of caregiver burden. Moreover, there is evidence that a large number of caregivers have rates of depressive symptoms as high as 38% to 60% (Zendjidjian et al., 2012).

Bipolar disorder can have a severe impact on the patient's family and caregivers. During episodes, partners can have significant problems in their relationships with patients, and these difficulties affect caregivers' own employment, legal matters, finances, and social relationships, including parenting (Dore G, Romans SE., 2001). In one study, 93% of caregivers reported moderate or great distress in at least one burden domain (Perlick D, Clarkin JF, Sirey J, et al, 1999).

Sharing a household with a person with bipolar disorder affects the physical health of family members, too. When other predictors of health were controlled for, people living with a person with bipolar disorder, regardless of the severity of the condition, reported poorer physical health, more limited activity, and greater health service utilization compared with others. (Gallagher SK, Mechanic D, 1996)

Sally Wai-chi Chan. (2011) in his study showed that there is a higher level of burden for caregivers of individual with mental disorder. Also he found relationships between socio-demographic and cultural characteristics of families and the burden. Moreover, results revealed that socio-demographic factors have an important role in the QoL of caregivers of individuals with mood disorders and schizophrenia.

Laurent Boyer et al. (2012) in their study on caregivers of patient with schizophrenia showed that they experience lower level of QoL especially on the mental scores. They indicated that having motherhood role was significantly associated with a lower QoL. Mothers may experience a higher burden because they are responsible for most aspects of the patients' daily care.

A study examined the quality of life of relative caregivers of hospitalized patients with mood disorders. Caregivers reported poor social, physical and emotional functioning. Family functioning was poor in the areas of roles, communication and affective involvement. In this study it was pointed out that the subjective burden, and not the objective one, was correlated with a poorer quality of life (Heru AM, Ryan CE, Vlastos K, 2002).

A qualitative research study was conducted in Canada among 52 caregivers of patients with bipolar affective disorder to assess their quality of life using a structured interview schedule. The result indicated that there was a complex, multifaceted relationship between bipolar disorder and quality of life. Most of the affected individuals reported that bipolar disorder had a profoundly negative effect upon their life quality, particularly in the areas of education, vocation, financial functioning, and social and intimate relationships (Nehra R, Chakrabarti S, Kulhara P, Sharma R., 2005).

A study was conducted on a sample of 59 depressed patients' spouses and 59 community controls to explore the QoL of spouses of patients with depression. In this study community controls reported better perceived social support including family, friend and significant others than the spouses of depressed patients. Also, the spouses of depressed patients reported poorer quality of life than the community controls. Also, older people reported poorer quality of life than people younger than 50 years. Women reported higher quality of life than men (Wang J. & Zhao X., 2012)

A cross-sectional study was conducted in London among 41 caregivers of patients with depressive psychosis to assess the quality of life of family members using the quality of life scale. The findings of the study indicated that family members were significantly distressed as a result of having a family member with psychotic depression and hence caregivers showed poor quality of life (Caqueo-Urizar A, Gutierrez-Maldonado J., 2006).

According to a descriptive study which evaluated the level of stress among family members of selected mentally ill patients, there was no significant difference between the stress of family members of schizophrenics and that of mood disorder patients (Barman N, Chakravortty P, 2012).

Concerning socio- demographic variables, most studies indicated that being woman, being older, being parent and having lower social class in terms of education and income are equal to more burden and consequently less quality of life among caregivers; meanwhile, there are some studies that showed contradictory findings which will be mentioned in the following.

A study showed that older caregivers experienced less QoL. Also, authors declared that parents and children had significantly lower QoL than siblings (Margetic, Jakovljevic, Furjan, Margetic, & Marsanic, 2013). Findings of some studies indicated that living with other family members in the same place may increase concerns related to other children in the family. Thus, the number of children especially when one of the parents is ill and the other is the caregiver, can affect the QoL of the caregiver (Knock, Kline, Schiffman, Maynard, & Reeves, 2011; von Kardorff, Soltaninejad, Kamali, & Eslami Shahrbabaki, 2016).

Findings of a study showed that there were no significant differences in the burden scores between caregiver subgroups in terms of gender, age, educational attainment, kinship with the patient and the patient's diagnosis (Fan & Chen, 2009). Results of a study also revealed that there was no significant relationship between gender and QoL while older caregivers showed less QoL and those who had higher education and income experienced higher QoL (Lua & Bakar, 2011). Conversely, another study indicated that there were no relationships between QoL and age, education and marital status (Wang & Zhao, 2012).

A qualitative study about experiences of parents living with and caring for their adult children with schizophrenia explored four major themes including psychological tsunami, caring activities, coping with enduring illness and an uncertain pathway.

The psychological tsunami theme describes the essence of the psychological trauma experienced by the parents, beginning with a foreboding that something was wrong with their offspring. The main factors that assisted the participants in coping with and adjusting to living with an offspring with schizophrenia were: antipsychotic medication, social support, spirituality, talking, length of time dealing with illness,

keeping busy, holidaying and a positive attitude (McAuliffe, O'Connor, & Meagher, 2014). According to a systematic review regarding burden of caregiving for patients with bipolar disorder, several characteristics of bipolar mania patient such as aggressiveness, lack of insight and financial problems were identified as severe burdens to caregivers (Beentjes, Goossens, & Poslawsky, 2012). A qualitative study about bipolar disorder pointed at the constant worries of caregivers about the future such as who would take care of the patient if they can no longer take care of him/her or if the patient can manage daily life. The authors also mentioned that the family members' future was associated with the unpredictability of the illness, lack of knowledge about outcomes, and pessimistic ideas about patient's ability to take care of himself/herself. When the family members also felt that there was no hope for improvement, their concern for the future became a heavier burden. Inspiring hope for the future was one of the useful strategies. It refers to the efforts the family members make when attempting to resume and get on with their own lives in the future. Belief in improvement of the illness could make the family members more hopeful. However, they also needed to see a future where they would no longer need to worry constantly (Jönsson, Skärsäter, Wijk, & Danielson, 2011).

Findings of a phenomenological study about family caregiving experience in Iran identified six main themes including fears and anxiety for the future, psychosomatic impact, feeling of isolation and loneliness, financial impact, change in lifestyle and family functioning and lack of support and knowledge. Seeking emotional and professional support, which are mentioned in this study, were a part of coping strategies of the caregivers (Shamsaei, Kermanshahi, Vanaki, Hajizadeh, & Hayatbakhsh, 2010). A "Grounded theory"[4] study identified two phases of coping

[4] "Grounded theory" is a methodology for qualitative empirical research, developed by Glaser and Strauss (B. Glaser); cf. actual state of the art: Charmaz 2006.

strategies. The initial phase was appraisal. The next step was searching for a balance between self-effacement (prioritizing the needs of others) and self-fulfillment (prioritizing one's own needs). The authors showed how caregivers tried to take their own needs more into consideration to come over the feeling of loneliness, as the core concept. The main strategy was having relationship with family including sharing feelings with them, trying to find support when participants spoke with others about their experiences and feelings or sought care and support from family, friends, and professionals, and finally increasing the personal space (Van Der Voort, Goossens, & Van Der Bijl, 2009).

Some qualitative studies about coping strategies among family caregivers of patients with severe mental illnesses showed a wide range of both useful and useless coping strategies. These strategies were resorting to religion, seeking support from family, friends and health- care professionals, increasing knowledge of mental illness, accepting it, engaging in leisure activities, resorting to traditional healing, ignoring the mentally ill person, isolating oneself, taking on all responsibility for the mentally ill person or controlling him/her, using verbal threats or abuse and so on (Ayuurebobi, Doku, Asante, & Owusu-Agyei, 2015; Azman, Jamir Singh, & Sulaiman, 2015; Hogan & John-Langba, 2016).

Relevant literature was identified by a systematic literature review by searching Medline through PubMed, ISI Web of Science, Science Direct and Google Scholar. Additionally, Iranian databanks including Iran Psych, Iranmedex and IranDoc were probed. All available Iranian psychiatric journals were also hand searched. Related studies regarding family caregivers of schizophrenics and affective disordered patients, their burdens and QoL, development and validation of an instrument to

measure QoL related to the aforementioned groups were searched. The studies were included if they had used a standardized interview or validated questionnaire.

Investigations of the main burdens, QoL, socio-demographic variables and coping strategies in the aforementioned studies indicated that there is no consensus between diverse studies. As the studies show contradictory results regarding QoL and main burdens of the three groups (caregivers of individuals with schizophrenia, BMD and MDD), the status of family caregivers in these groups is not clear. Thus, some questions can be posed including what are the specific burdens of family caregivers in these groups? And what are the differences between these groups in terms of QoL?

One of the controversial aspects is the relationship between socio-demographic variables and family caregiver QoL. Studies do not show an agreement on this issue. While some studies indicated that being woman or mother, being older, living with the patient and other family members in the same home and having lower social class are associated with lower QoL, other studies show opposite results. Thus, there is a need for a multidimensional approach or a mixed method study to demonstrate which socio-demographic factors could have a relationship with family caregiver's burden and QoL?

Regarding coping strategies, most studies have traditionally focused on problem-focused and emotion-focused strategies by using some questionnaires as the tools of a quantitative approach while a qualitative approach can explore new dimensions of coping strategies from the point of view of the caregivers. Because there are a few qualitative studies regarding coping strategies in family caregivers of mental illnesses, a comprehensive qualitative approach including family caregivers of

schizophrenics and affective disordered patients could fill the gap of the state of current researches about what main coping strategies caregivers adopt, from a subjective perspective.

Chapter 3: Methodology

3.1. Introduction

In order to attain the objectives of this study, it was important to use an effective method to gather high quality data about the main burdens that caregivers of mentally ill patients experienced, factors which were related to quality of life of caregivers and finally in-depth information regarding these factors. Among several methods that can be used for collecting this data, the three phase model (mixed method)[5] has been chosen to ensure that all aspects of caregiving in terms of experienced burdens and quality of life have been considered. In this study, in the first phase, which is qualitative, in- depth information about the main burdens that caregivers endure were provided; in the second phase, the quantitative one, a tool has been developed and validated to measure quality of life of caregivers of individuals with mental illness. Then, according to quantitative data obtained from the second phase, a third phase, which is again qualitative, was designed to more profoundly explore aspects of main factors which contribute to quality of life.

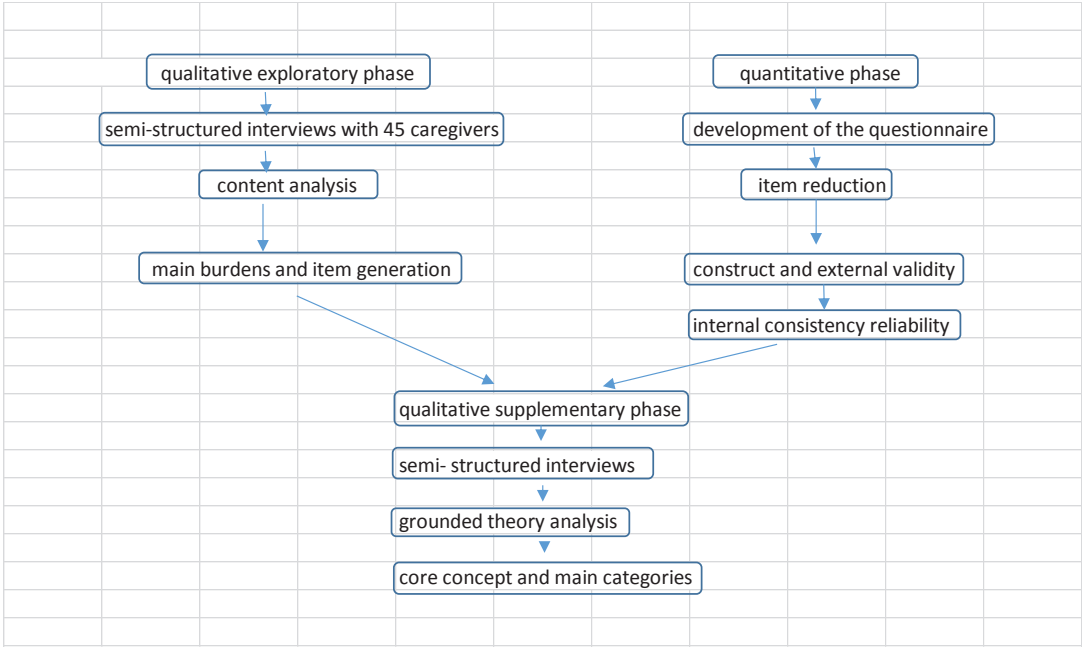
This chapter explains methods used in this study. It elaborately describes three phases of the study including way into the field, data collection, sampling and recruitment procedure, data analysis and ethical approval processes.

[5] Mixed methods research is a special case of multi-method research. It includes the mixing of qualitative and quantitative data and methods. Current study is based on *Qualitatively driven approaches/designs* in which the research study is, at its core, a qualitative study with quantitative data/method added to supplement and improve the qualitative study by providing an added value and deeper, wider, and fuller or more complex answers to research questions; qualitative quality criteria are emphasized but high quality quantitative data also must be collected and analyzed (R. B. Johnson, Onwuegbuzie, & Turner, 2007).

3.2. Research design

In the current study a sequential mixed method design with three phases was chosen (Christensen, Johnson, & Turner, 2011; R. B. Johnson et al., 2007). Information resulted from the first qualitative phase construct the raw material of the second phase. After testing the raw materials, a validated tool (questionnaire) was developed. According to the dimensions and their respective items in the questionnaire, the third qualitative phase was designed in order to provide in-depth information about quality of life of caregivers and to find the core concepts of caregiving. These three phases are illustrated in figure 1.

Figure1. Three abstracted phases of the study



3.3. The qualitative exploratory Phase

The study was conducted in the Shahid Beheshti Psychiatric Hospital in Kerman (Iran), which has about 200 psychiatric inpatient beds. The non-representative sample was selected from caregivers while they were attending their relative who was an inpatient in the hospital. To participate in the study, the caregivers themselves should not suffer from mental illness (confirmed by a psychiatrist). The use of purposive sampling[6] among caregivers of current inpatient clients, in contrast to systematic theoretical sampling in a natural setting, was partly due to practical reasons (access, time, money); nonetheless, the purposive sampling procedure allowed a post factum analysis to obtain maximal contrasts and variation in the caregivers' family situation with reference to the criteria found in the existing literature (cf. chapter 2) on family caregivers. The decision regarding which participants to include was made by experienced psychiatrists at the clinic (Shahid Beheshti Hospital) in accordance with the diagnostic inclusion criteria of the study. Family caregivers were recruited based on the illness of their inpatient relative, gender, age, length of time they had been providing care, and their type of relationship with the patient. All participants had relatives who remained inpatients, and for whom they provided care throughout the study. Inclusion criteria for

[6] Purposive sampling, also known as judgmental, selective or subjective sampling, is a type of non-probability sampling technique. Purposive sampling relies on the judgment of the researcher when it comes to selecting the units (e.g., people, cases/organizations, events, pieces of data) that are to be studied. The main goal of purposive sampling is to focus on particular characteristics of a population that are of interest, which will best enable you to answer your research questions. The sample being studied is not representative of the population, but for researchers pursuing qualitative or mixed methods research designs, this is not considered to be a weakness. There are a wide range of purposive sampling techniques that we chose the maximum variation technique. Maximum variation sampling, also known as heterogeneous sampling, is a purposive sampling technique used to capture a wide range of perspectives relating to the thing that you are interested in studying. The basic principle behind maximum variation sampling is to gain greater insights into a phenomenon by looking at it from all angles. This can often help the researcher to identify common themes that are evident across the sample (Mujere, 2016; Patton, 2005).

patients included age (15_65), diagnosis of schizophrenia or affective disorder according to DSM-IV, and availability of caregivers for assessment. Illness duration of at least one year was required for inclusion in the study. Caregivers needed to be identified as a family caregiver, aged at least 18 years, for either a patient with schizophrenia or an affective disorder. Informed consent was provided by each caregiver in order to participate in a semi structured interview. The interviews were carried out in the clinic after the caregivers had visited their patients in the clinic. Each interview started with open narration-generating questions, such as "would you please tell me when the disease of your patient began?" and "Can you tell me about your first ideas, emotions, and actions?" The following questions in the interview process were posed according to an interview guideline, which was based on the respective literature as well as on previous pre-test interviews with the respondents, who were asked to speak freely about their personal experiences in the caregiving process and in the lived experiences of the reactions of their wider family, workmates, and neighbors. All interviews were audio taped and transcribed. The interviews continued until data or Theoretical saturation[7]; ultimately, 45 interviews were conducted. The interviews lasted from 18 to 50 min. with an arithmetic mean of 30.2 min duration.

[7] Data Saturation is usually explained in terms of "when no new data are emerging." But saturation is more than a matter of no new data. It also denotes the development of categories in terms of their properties and dimensions, including variation, and if theory building, the delineating of relationships between concepts (Corbin & Strauss, 2014). Theoretical saturation means that new data in further data collection did not bring new insights into the theoretically extracted categories, thus there is no change in the core concepts of the analysis during initial, axial and fine-coding. Theoretical saturation, in effect, is the point at which no new insights are obtained, no new themes are identified, and no issues arise regarding a category of data (Strauss and Corbin, 1990). At this milestone, the data categories are well established and validated. Glaser and Strauss (1967: 65) explain in their seminal work, The Discovery of Grounded Theory, that 'when one category is saturated, nothing remains but to go on to new groups for data on other categories, and attempt to saturate these categories also'. It stands to reason that, as Morse (1995) points out, saturation of all categories signifies the point at which to end the research (Bowen, 2008).

Deductive and inductive content analysis was used for data analysis. For qualitative data analysis, an inductive approach according to grounded theory (GT) was used (Berelson, 1952; Polit-O'Hara & Beck, 2006; Schreier, 2012; Sreeja, 2013). Following the methodology of GT, the transcribed interviews were coded. (A description of the coding procedure has been indicated in Table 4). During the analysis process, the authors focused on both manifest and latent topics. The transcribed texts of the interviews were reviewed several times so that an inter-subjective shared understanding of the given answers could be assured. The first step of coding was done to get categories from the statements. The comparison of statements resulted in primary categories. In the second step of coding, the primary categories were reviewed and categories that contained the same content were further categorized to obtain a concluding set of relevant topics. To determine the validity of the results, the interviews were read frequently so that the researchers could introduce their ideas every place it seemed to be necessary. An additional coder who was not involved in the interview process was trained and independently coded 5 interviews that were randomly chosen from the set of 45 transcripts. Finally, the coding of the additional rater was compared with the results of the primary rater for reliability using Cohen's kappa. Inter-rater reliability was calculated to be 0.73, 0.78, 0.73, 0.73 and 0.77 for the five interviews. The overall reliability was 0.75.

The ethics committee of the psychiatric hospital at the Kerman University of Medical Sciences approved the study. All of the participants were given oral and written information regarding the purpose and relevance of the study. Oral and written informed consent was provided by the family caregivers and they were free to leave the study whenever they wanted. The interviews were performed anonymously using a number-based identification system.

3.4. The quantitative Phase

A self-administered, multidimensional QoL instrument is developed and validated based on the triangulation technique[8] (Yeasmin & Rahman, 2012). Face to face semi-structured interviews with 45 caregivers and expert panel were done; prior questionnaires regarding QoL of both general and specific populations such as WHOQOL-BREF, S-CGQoL, CARGOQoL were collected and QoL index and quantitative method were applied (Ferrans & Powers, 1992; Minaya et al., 2012; Richieri et al., 2011; Schene, Tessler, & Gamache, 1996; Usefy et al., 2010).

In this phase of the study data were collected from two psychiatric hospitals and one charity center in Tehran and Kerman (Iran): Shahid Beheshti (Kerman), Razi (Tehran) and charity center of Golestane salamat (Kerman). Razi Hospital is the biggest psychiatric center in the Middle East which has about 1375 psychiatric inpatient beds and Golestane salamat is a charity with about 300 inpatient beds. The inclusion criteria for the caregivers were similar to the inclusion criteria of the exploratory qualitative phase. The exclusion criteria for the caregivers were living with another family member who suffers from a chronic illness except for a psychiatric illness.

For a period of three months the author and his collogues identified caregivers of individuals with schizophrenia and affective disorders who had the role of main caregiver by asking the patient or medical staff. Then the research group asked the patients if they can contact the caregivers. When the patient consented and when

[8] 'Triangulation' is a process of verification that increases validity by incorporating several viewpoints and methods. In social sciences, it refers to the combination of two or more theories, data sources, methods or investigators in one study of a single phenomenon to converge on a single construct, and can be employed in both quantitative (validation) and qualitative (inquiry) studies (Yeasmin & Rahman, 2012).

the caregivers met the inclusion criteria and they accepted to participate in this study, the self- report questionnaires were distributed among caregivers.

3.4.1. Data collection

The original questionnaire (cf. Appendix F, P: 137) comprised of the following four primary parts:

1. written consent in the beginning of each questionnaire which every participant should read and decide if he/she intends to participate in this study and continue to answer the questions;
2. initial self-administered questionnaire including sixty-seven questions derived from semi-structured interviews, prior questionnaires regarding QoL for both general and specific populations such as S-CGQoL, CARGOQoL and QoL index, comments of experts and comments of some caregivers (Ferrans & Powers, 1992; Minaya et al., 2012; Richieri et al., 2011; Schene et al., 1996);

   Based on the information acquired from phase I, both the main burdens which caregivers experience and raw materials for developing the questionnaire were obtained. Seventy four questions were identified from the interviews in the exploratory qualitative phase. These items were answered using a six- point Likert scale, defined as “1: not at all”, “2: a little”, “3: somewhat”, “4: a lot”, “5: very much” and outside the Likert-logic “6: not applicable”.

   According to the experts and caregivers’ comments on any aspect of the questionnaire, items that were ambiguous, misunderstood and rarely answered were reworded or deleted. Finally, it led to a primary

questionnaire that comprised sixty seven items. Item generation by means of interviews with caregivers ensured content validity because it reflected the concrete experience of caregivers. On the other hand, comments of experts and caregivers on the raw materials of questionnaire ensured face validity.

3. socio-demographic characteristics of the caregivers including gender, age, educational level, marital status, duration of caregiving, residence status, job status, income and expenditure amount, number of children and their skills;
   in addition to socio- demographic characteristics of patients including gender, age, type of illness and relationship with caregiver;
4. WHO- QOL (Short Form);
   It is a validated generic, self-administered QoL questionnaire, consisting of 26 items describing 4 dimensions: physical health, psychological and social relationship and the environment. Each dimension is scored within a range of 4 to 20 or 0 to 100 (WHO, 1996).
   Usefy, et al. (2010) investigated the reliability and validity of WHO-QOL BREF in an Iranian population consisting of 2,936 clinical and 2,956 non clinical subjects. Accordingly, the Cronbach's alpha for the entire sample, the clinical, and the non-clinical samples were 0.82, 0.82, and 0.84, respectively. Additionally, its construct validity in healthy and unhealthy Iranian population was approved of.

3.4.2. Item reduction and validation of the questionnaire

Item reduction was based on experts and statistical analysis. To reduce the number of items, each of sixty-seven items was reviewed for adverse characteristics related to item distribution (Crocker & Algina, 1986).

The first step of item reduction took place according to the following:

1. comments of experts;
2. more than 15% missing data;
3. over 70% ceiling or floor effects;
4. absolute value of skewness more than 4;
5. correlation coefficients with other items over 0.8.

At the end of these steps, 15 items were removed.

Construct validity defines the construct to be measured by the instrument and assesses the internal structure of its components and the theoretical relationship of its items and subscale scores. It was assessed using principal component factor analysis with varimax rotation (Nunnaly and Bernstein, 1994) in order to determine the final structure and the number of independent dimensions (Richieri et al., 2011).

Also, construct validity can be measured using the known group approach, convergent and discriminant validity. These are explained after factor analysis method.

The second step of item reduction was designed according to the fundamental factor analysis. It took place according to the following:

1. correlation matrix: R type
2. factor model: Principal component analysis
3. extraction method of factors: orthogonal
4. rotation type: Varimax
5. criterion for number of factors:
   1) eigenvalue more than 1(Kaiser & Caffrey, 1965)
   2) percentage of explained variance: more than 60
   3) loading factor: greater than 0.4
6. item removal: items with low psychiatric performance at a dimension level were deleted based on inter-item, item-dimension and inter-dimension correlations. At the end other 24 items were removed at this step.

Ultimately, the final version of questionnaire with 28 items and 7 dimensions was obtained and each dimension was named based on its constituent items.

3.4.3. Divergent validity

It refers to comparisons of mean or correlations between our questionnaire and socio-demographic variables based on the following hypotheses:

1. Caregiving duration is positively correlated with the caregiver quality of life. Increase in caregiving duration may decrease caregiver quality of life.
2. Caregivers of individuals with major depression disorder experience higher levels of QoL than caregivers of individuals with bipolar mood disorders or schizophrenia.

3. There is no difference between QoL of caregivers of schizophrenics and bipolar mood-disordered patients.

   The comparisons of means were performed using student's t- test and analysis of variance (ANOVA).

   Data analysis was performed using SPSS 22.

3.4.4. Internal consistency reliability

It refers to the strength of the correlation between items within each domain of the questionnaire and between all items in the questionnaire.

It was carried out by calculating the Cronbach's alpha coefficient (A coefficient of at least 0.7 was expected for each dimension) (Cronbach, 1951).

The process of item-reduction is mentioned precisely in the result section.

3.4.5. Convergent validity

It is examined by assessing the correlations of dimension scores of our questionnaire with the scores of the WHO-QOL (Short Form).

The fundamental assumption is that dimension scores of our questionnaire would be more correlated with scores of similar dimensions of WHO-QoL than with dissimilar ones.

3.5. The qualitative supplementary Phase

This phase of study was conducted in the inpatient and outpatient wards of Shahid Beheshti Psychiatric Hospital which is located in Kerman (Iran). Theoretical sampling was used for this phase of study according to the acquired information from data analysis of both the exploratory qualitative phase and the quantitative phase. To participate in the study, caregivers themselves should not have suffered from mental illness (confirmed by a psychiatrist). The decision regarding which participants to include was made by experienced psychiatrists at the clinic (Shahid Beheshti Hospital) in accordance with the diagnostic inclusion criteria of the study. Family caregivers were recruited based on education level, income status and their profession. It was tried to find some family caregivers with high contrasts in terms of the three aforementioned factors who lived in city and countryside. The level of education was divided into two categories of high and low and profession was categorized as either independent or dependent. All participants had relatives who remained inpatients, and for whom they provided care throughout the study. Inclusion criteria for patients were age range of 15_65, diagnosis of schizophrenia or affective disorder according to DSM-IV, and availability of caregivers for assessment. Illness duration of at least one year was required for inclusion in the study. Caregivers needed to be identified as a family caregiver, aged at least 18 years, for either a patient with schizophrenia or an affective disorder. In order to participate in a semi-structured interview, informed consent was obtained from each caregiver. The interviews were carried out in the clinic after the caregivers had visited their patients. Each interview started with open narration-generating questions, such as “would you please tell me how and when problems with your sick family member started?”, “Can you tell me about your story?” and “would you please tell me from the beginning up to now?” In this part of interview, the interviewer let the family

caregivers to tell freely about their story, ideas, emotions and everything that they wanted to state. The following questions in the interview process were posed according to an interview guide, which was based on the respective literature as well as on previous phases of the study. These questions included: “would you please tell me about your experience with the psychiatric system, doctors and nurses?” or “would you please tell me about your experiences about troubles in everyday life and changing relationships?” and so on. At the end of interviews the interviewer posed some questions such as: “what do you think about the future” or “is there anything else you can think of that you have not told me?” All interviews were audio taped and transcribed. The interviews continued until data saturation. Saturation is usually explained in terms of “when no new data are emerging.” But saturation is more than a matter of no new data. It also denotes the development of categories in terms of their properties and dimensions including variation, and if it is concerned with theory building, it delineates relationships between concepts. (Straus and Corbin, 2007); ultimately, 18 interviews were conducted. The interviews lasted from 30 to 60 min, with an arithmetic mean of 43.7 min duration.

Grounded Theory (GT), as the basis of qualitative research, was used for data analysis (Charmaz, 2014; Corbin & Strauss, 2014; B. G. Glaser & Strauss, 2009). Following the methodology of GT, the transcribed[9] interviews (cf. data on CD-ROM) were coded.

During the analysis process, the authors focused on both manifest and latent topics. The transcribed texts of interviews were reviewed several times so that an inter-subjective shared understanding of the given answers could be assured. The first step of coding was done to get categories from the statements. During the initial

[9] The author did not follow a special method.

coding it was tried to see actions in each segment of data. Line-by-line and incident-by-incident coding method using gerunds were applied in order to detect processes and stick to data. Constant comparative method (Glaser and Strauss, 1967) helped establish analytic distinctions and thus make comparisons at each level of analytic work. The comparison of statements resulted in primary categories. In the second step of coding, primary categories were reviewed and groups that contained the same content were further categorized to obtain a concluding set of relevant topics. In the process of focused coding, the most significant or frequent codes of the initial coding which had the most analytic sense for categorizing data, were used. Relating categories to sub-categories, specifying properties and dimensions of a category and reassembling the fractured data during initial coding occurred during axial coding in order to bring data back together again in a coherent whole. During the interpretation and coding process the core concept was developed gradually and finally, more insight was obtained concerning family caregiver experience through identifying facilitative and deleterious variables of the core concept.

3.6. Ethical considerations

1. Caregivers had been asked to participate in this study voluntarily.

   At the beginning of each interview, aim of the study will be explained to participants;
2. Verbal information will be provided according to the interview guide (cf. Appendix E).
3. Voice will be recorded with the permission of participants.
4. It will be explained to participants that they can exit from the study any time they wish.
5. Participants will be asked to sign a participation consent form.
6. Participants' names will not be required on questionnaires and other forms of identity will not appear anywhere in the report or in subsequent publications.
7. The interviews were performed anonymously using a number-based identification system.

Chapter 4: Results

4.1. Introduction

The results of three phases of the study are presented in this chapter. In the first section of each phase, demographic characteristics of the sample are shown. Then, the main results of each phase are reported.

4.2. Results of qualitative exploratory phase

4.2.1. Demographic characteristics of the sample

A content analysis was applied to summarize 816 statements made by the caregivers in 45 categories and 11 themes. Generic characteristics of both the patients and their caregivers have been provided in tables 2 and 3, respectively.

Table 2 summarizes demographic characteristics of the patients. The number of people with schizophrenia and affective disorders were 20 and 25, respectively. There are 8 (40%) paranoid schizophrenics and 12 (60%) non-paranoid schizophrenics.

Fourteen (70%) patients with schizophrenia were male and six (30%) of them were female. Also, nineteen (76%) of affective disordered patients were male and six (24%) were female. The mean age of patients with schizophrenia and affective disorders were 37.65 and 37.36 years old, respectively. Furthermore, some other characteristics of patients such as marital status, duration of illness, employment status, education level and residence status are presented in table 2.

Table 3 shows demographic characteristics of caregivers. There are 6 (30%) male and 14 (70%) female caregivers of schizophrenics; and 6 (24%) male and 19 (76%) female caregivers of affective disordered patients. The mean age of caregivers of schizophrenia and affective disorders were 42.20 and 44.92 years old, respectively. Some other characteristics of caregivers such as marital status, relationship with patient, duration of care, employment status, education level, residence status and weekly contact with patient has been presented in table 3.

Table 2. Characteristics of the patients (n=45)

Characteristic	Schizophrenia n (%)	Affective disorders n (%)
N	20	25
Gender		
Male	14 (70)	19 (76)
Female	6 (30)	6 (24)
Age (M)	37.65 years	37.36 years
Marital status		
Divorced/ never married/ widowed	9 (45)	16 (64)
Married	11 (55)	9 (36)
Duration of illness (M)	10.35 years	7.60 years
Employment		
Full time/ part time	2 (10)	4 (16)
Unemployed/ retired/ student	18 (90)	21 (84)
Education		
Illiterate	1 (5)	2 (8)
Primary	6 (30)	3 (12)
Secondary	2 (10)	9 (36)
High school diploma	9 (45)	9 (36)
College	2 (10)	2 (8)
Residence		
Urban	16 (80)	16 (64)
Rural	4 (20)	9 (36)
Schizophrenia subtype		
Paranoid	8 (40)	---
Non paranoid	12 (60)	---

Table 3. Characteristics of the caregivers (n=45)

Characteristic	Caregivers of schizophrenia n (%)	Caregivers of affective disorders n (%)
N	20	25
Gender		
Male	6 (30)	6 (24)
Female	14 (70)	19 (76)
Age (M)	42.20 years	44.92 years
Marital status		
Divorced/ never married/ widowed	5 (25)	6 (24)
Married	15 (75)	19 (76)
Relationship: caregiver is patient's		
Spouse	9 (45)	8 (32)
Parent	5 (25)	9 (36)
Child	2 (10)	2 (8)
Sibling	4 (20)	6 (24)
Duration of care (M)	8.82 years	6.92 years
Employment		
Full time/ part time	9 (45)	7 (28)
Unemployed/ retired/ student	11 (55)	18 (72)
Education		
Illiterate	2 (10)	4 (16)
Primary	4 (20)	8 (32)
Secondary	2 (10)	6 (24)
High school diploma	8 (40)	4 (16)
College	4 (20)	3 (12)
Residence		
Urban	15 (75)	16 (64)
Rural	5 (25)	9 (36)
Caregiver and patient living together		
Yes	16 (80)	19 (76)
No	4 (20)	6 (24)
Weekly contact with patient (hr)		
Up to 5	4 (20)	5 (20)
6-15	5 (25)	7 (28)
16-35	5 (25)	8 (32)
More than 35	6 (30)	5 (20)

For a better understanding of how the 11 higher order themes were derived from the 45 lower order categories, which were generated from the interviews, a matrix was developed (cf. table 4). Also, the rank of the most frequent burdens among caregivers of schizophrenia and affective disorders has been compared (cf. table 5).

Table4. The matrix presenting themes and main categories of caregiver burden in patient with schizophrenia and affective disorders.

Themes	Main Categories	N (%)
Emotional burden	caregiver's grief, mental strain and feeling of loss	44 (97.8)
	caregiver's feelings of shame and embarrassment	36 (80.0)
	caregiver's anger at the behavior of the patient	20 (44.4)
	caregiver's guilt	19 (42.2)
	caregiver's feelings of fear, anxiety and consternation	9 (20.0)
	boring and monotonous life	6 (13.3)
	caregiver's lack of feelings of happy, vitality and pleasure	8 (17.8)
	lack of peace and safety feelings	9 (20.0)
Unawareness	lack of understanding patient's behavior and managing bizarre and disruptive behaviors	40 (88.9)
	lack of enough information about illness and process of treatment	37 (82.2)
	caregiver's dissatisfaction with information given by doctors and nurses	10 (22.2)
Incertitude	caregiver's worries about future and possibility of self- subsistence of the patient	38 (84.4)
	caregiver's worries about its own future	21 (46.7)
	caregiver's worries about future of other family members	35 (77.8)
	caregiver's worries about patient's suicide	11 (24.4)
	caregiver's worries about patient hurts itself	6 (13.3)
	caregiver's worries about patient hurts others	9 (20.0)
	caregiver's worries about patient hurts him/her	9 (20.0)
Stigma and blame	caregiver's distress for stigma and blame	36 (80.0)
	caregiver's distress related to use of professional help	21 (46.7)
Financial burden	financial troubles	38 (84.4)
	housing problems	9 (20.0)
Physical burden	caregiver's physical problems because of patient's illness	15 (33.3)
	caregiver's feeling of tiredness	17 (37.8)
	caregiver's lack of energy and enough ability	10 (22.2)
	caregiver's dissatisfaction with its sleep	8 (17.8)
Restriction in routine	limitation and restriction in everyday life	25 (55.6)
	give up beloved things and disruption in leisure times	13 (28.9)
	to reduce relationship with family, friends and acquaintances	30 (66.7)
Disruption in routine	disruption in family life and routine	17 (37.8)
	increase in caregiver's workload because of its caregiving role	11 (24.4)
	caregiver's problems in division of labor and responsibility in the everyday family work	11 (24.4)
	caregiver's neglect of own and other family members because of patient' illness	6 (13.3)
Dissatisfaction with family, relatives and acquaintances	caregiver's lack of help and support by extended family, friends and acquaintances	32 (71.1)
	lack of understanding of caregiver by family and acquaintances	25 (55.6)
	conflicts in everyday life	27 (60.0)
	lack of undertaking the role of caregiving by others	5 (11.1)
	dissatisfaction with emotional and sexual life	20 (44.4)
Burden related to medication	caregiver's distress about adherence in taking medications and taken at appropriate times	19 (42.2)
	caregiver's difficulties about medication provision	6 (13.3)
Troubles related to health services and governmental support	lack of support by governmental organizations	8 (17.8)
	caregiver's dissatisfaction with hospital services	10 (22.2)
	insurance troubles	12 (26.7)
	transportation difficulties	8 (17.8)
	problems with being available health care services	10 (22.2)

Table5. Rank of the most frequent main categories among caregivers of schizophrenia and affective disorders

	BURDENS	Rank of caregiver's burden of		
		Schizophrenia	BMD*	MDD*
	lack of understanding patient's behavior and			
1	managing bizarre and disruptive behaviors;	1	2	6
	helplessness and hopelessness of the caregiver			
2	caregiver's grief, mental strain and feeling of loss	2	1	1
3	caregiver's worries about future and	3[a]	4	5
	possibility of self- subsistence of the patient			
4	caregiver's worries about future of	3	9	4
	other family members			
5	lack of enough information about	4	5	7
	illness and process of treatment			
6	financial troubles	5	3	2
7	caregiver's feelings of shame and embarrassment	6	7	11
8	caregiver's anger at the behavior of the patient	7	18	22
9	caregiver's worries about its own future	7	25	23
10	caregiver's distress for stigma and blame	8	9	3
11	lack of understanding of caregiver by family and acquaintances	20	6	30
12	caregiver's lack of help and support by	15	8	6
	extended family, friends and acquaintances			
13	caregiver's distress related to use of professional help	19	17	6

*BMD= Bipolar Mood Disorder

*MDD= Major Depression Disorder

a= some of the ranks are equal among some burdens for example rows 3 and 4 both have a rank of 3. This is according to the number of main categories among these three groups.

4.2.2. The main themes

The main themes are mentioned below:

Incertitude

Most participants acknowledged that they experienced uncertainty due to the unpredictable nature of and ambivalence about the disease, as well as about the treatment process and the future. One of the caregivers declared: *"I am worried about his future. I look after him as long as I am alive. When I die, who will take care of him? I am worried that he may never be able to take care of himself."*

Unawareness

The majority of caregivers did not have enough information about the disease or the treatment. Furthermore, they were dissatisfied with the information given to them by doctors and nurses. A caregiver said: *"When I faced this illness, I did not know about the illness. I did not know what I should do. I did not know what schizophrenia is about."*

Emotional burden

This comprises a variety of stressors related to care, including grief and depression, as well as feelings of shame, embarrassment, fear, anxiety, consternation, guilt and anger. Most caregivers experienced high rates of these feelings that could affect their own mental health. One participant said: *"I felt a lot of grief. I said to myself, o'God! Why is my child so?"*

Another caregiver said: *"I felt so sad because I could not bear that he hurts himself. I could not bear his attempts to commit suicide, because I could not do anything."*

Stigma and blame

The majority of caregivers indicated worries and distress about stigma and blame from the larger family and relatives.
One participant stated: *"We don't have any prestige because of my mother's behaviors. Neighbors say that your mother is mad. They blame me and say that your mother shows these behaviors deliberately."*

Stigma and blame are the most important reasons for concealment of illness and not seeking professional help among caregivers, especially caregivers of people with major depression disorders (MDD).
A mother expressed her concern about using professional help: *"No one knows that I hospitalize my daughter in this hospital because people say that my daughter is mad and she has been hospitalized in an asylum. They don't know that this isn't an asylum but a psychiatric hospital to care for these patients."*

Financial burden

Financial burden is one of the most important burdens reported in most relevant research. One participant described how financial problems have affected her life: *"My husband doesn't have any job and I don't have any money to hospitalize my son in this hospital. Furthermore, I should provide a trousseau for two more daughters, but I don't have anything."*

A few participants mentioned difficulties about housing*: "for several years, we have rented our home and our landlord has warned us permanently regarding our past due rent, electricity, and water bill."*

Physical burden

This includes somatic complaints, lack of energy, sleep disturbances and feelings of exhaustion and tiredness. One spouse complained about somatic pain attributed to the strain of caregiving. She stated: *"I have been affected by thousands of somatic pains, such as backache, headache, lumbar disk and leg pains."*

Restriction in routine

Some caregivers stated that they feel restrained in their freedom to act: they experienced various restrictions in everyday life and they had to give up things that they previously enjoyed doing. Diminished relationships with relatives and restrictions in leisure activities were two of the more significant restraints reported by the interviewees.

A sibling participant said: *"I can't go anywhere. I can't go on a trip. I must always accompany her and look after her. Whenever I go out, I have to come back early."*

Disruption in routine

A large number of family caregivers, especially caregivers of schizophrenia patients, highlighted disruptions in their everyday life and in their way of living. Increased workload, difficulties in division of labor and responsibilities in everyday family tasks, and negligence of caregivers toward themselves and other family members are reported here as main problems. One participant declared: *"I have to manage all*

tasks at home by myself. If a door is out of order, he doesn't fix it. He doesn't manage any task at home anymore."

Dissatisfaction with family, relatives, and acquaintances

This comprises some of the most important problems experienced by caregivers: lack of help and support by family and acquaintances, especially the feeling of lack of understanding and empathy, conflicts with others, lack of being supported in the caregiving role by others, and dissatisfaction with emotional and sexual life. All of these result in a gradual process of feelings of inner and factual isolation. A child participant said: *"No one supports me. No one understands me. I become exasperated with acquaintances. In other families, maybe one person doesn't understand. In my family, no one understands."*

Troubles with patients' adherence to medication

Both medication compliance by the patient and provision of medication were the main problems reported under this category. One participant said: *"He doesn't take his drugs on time or puts it under his tongue and then throws it out. I have big problems with medication adherence by my patient."*

Problems with health services and governmental support

Some participants mentioned lack of governmental support and services. This refers to the availability of health services, as well as troubles with health insurance and transportation difficulties. As a sibling participant reported: *"My brother cannot work. On the other hand, the welfare organization doesn't accept him as a member to support him because they say that my brother is an addict."* Another participant

said: *"Help Committee supports me just for $20 per month and it is not sufficient for my expenses."*

4.3. Results of quantitative phase

4.3.1. First factor analysis

The caregivers' characteristics of the first sample for factor analysis are mentioned below. Of the 232 caregivers identified by the patients, 24 caregivers refused to participate in this study and 8 caregivers did not fill out the questionnaire properly. Therefore, our sample consisted of 200 caregivers. The average age of caregivers was 43.15 years (SD=10.08) and 49.5 percent of them were unemployed. The characteristics of the caregivers are shown in table 6.

Table6. Characteristics of the caregivers related to the first-factor analysis.

Statistics	N	%
Sex		
Female	122	61
Male	72	36
Miss	6	3
Caregiving duration Mean	8.13±5.71	
Relationship with patient		
Spouse	38	19
Parent	47	23.5
Child	44	22
Sibling	63	31.5
Other	6	3
Miss	2	1
Under supporting of welfare organization		
Yes	65	32
No	101	50
Not applied	22	11
Miss	12	7
Type of residence		
Owner	86	43
Rental	100	50
Other	6	3
Miss	8	4
Income Mean per month	330$	
Employment		
Unemployed	99	49.5
Full time	30	15
Part time	32	16
Retired	20	10
Early retired	5	2.5
Miss	14	7
Place of residence		
Urban	157	78.5
Rural	40	20
Miss	3	1.5
Use of rehabilitation services		
Yes	69	34.5
No	124	62
Miss	7	3.5
Number of children Mean	3.05±2.36	
Age Mean	43.15±10.08	
Education		
Illiterate or elementary	121	60.5
Secondary	46	23
College	33	16.5
Marital status		
Married	126	63
Single	74	37
Type of illness		
Schizophrenia	80	40
BMD	63	31.5
MDD	55	27.5
Miss	2	1
Evaluating caregiving burden	4.32±1.06	

Based on exploratory factor analysis (principal components) and varimax rotation mentioned in chapter 3, the results mentioned in tables 7 and 8 are obtained.

Table 7. KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.789
Bartlett's Test of Sphericity	Approx. Chi-Square	2551.585
	Df	253
	Sig.	.000

Table8. Factor loadings for the seven extracted subscales after varimax rotation

	Component						
	1	2	3	4	5	6	7
Q1	0.825						
Q2	0.819						
Q3	0.766						
Q4	0.775						
Q9	0.641						
Q10	0.709						
Q21				0.735			
Q22				0.792			
Q23		0.873					
Q24		0.806					
Q31		0.712					
Q13			0.872				
Q14			0.917				
Q15			0.81				
Q37							0.802
Q41							0.653
Q35						0.892	
Q36						0.882	
Q16					0.921		
Q17					0.911		
Q32	0.687						
Q25	0.634			0.469			
Q26	0.699						

The seven-factor structure that was mentioned above explained 74.56% of the total variance. The questions resulted from the first factor analysis which were categorized into seven dimensions are mentioned below.

1) Emotional burden

Q1. Have you felt sad/depressed?

Q2. Have you felt exhausted?

Q3. Have you felt that you lack energy?

Q4. Have you been tired/worn-out?

Q9. Have you felt that you weren't free?

Q10. Have you felt that you led a day-to-day life?

Q25. Have you felt helpless?

Q26. Have you felt hopeless?

Q32. Have you felt embarrassed?

2) Dealing with patient's symptoms

Q23. Have you been able to understand your patient's behavior?

Q24. Have you been able to manage bizarre and disruptive behaviors of your patient?

Q31. Have you had enough information about illness and process of treatment?

3) Relationship with therapeutic team

   Q13. Have you been understood by doctors and nurses?

   Q14. Have you been helped/supported by doctors and nurses?

   Q15. Have you been satisfied with the information given by doctors and nurses?

4) Financial burden

   Q21. Have you had financial difficulties in treating your family member's illness?

   Q22. Have you had housing and transportation difficulties?

5) Relationship with family

   Q16. Have you been understood by your family?

   Q17. Have you been helped/supported by your family?

6) Relationship with extended family and friends

   Q35. Have you been understood by your extended family and friends?

   Q36. Have you been helped/supported by your extended family and friends?

7) Stigma

   Q37. Have you been worried about going to the psychiatric hospital or psychiatrist?

   Q41. Have you had to reduce contacts with extended family and friends because you felt ashamed?

This version of the questionnaire had some small changes in grammar and wording and also five new questions were added according to the expert panel and a final version was provided for repeating factor analysis. If the results of this part are similar to the first factor analysis and psychometric

properties like face and content validity, construct validity and reliability, and external validity are good, it is a suitable test to use in the aimed population in order to measure quality of life.

4.3.2. Second factor analysis

Of the 226 caregivers who were eligible to participate in this study, 18 caregivers refused to participate in the study and 12 caregivers did not fill out the questionnaire properly. Therefore, our sample consisted of 196 caregivers. The characteristics of the caregivers and patients are shown in table 9 and 10.

Table9. Characteristics of the caregivers

Statistics	N	%
Sex		
Female	159	81.1
Male	36	18.4
Miss	1	0.5
Marital status		
Married	129	65.8
Single	32	16.3
Divorced	28	14.3
Widow	5	2.6
Miss	2	1
Relationship with patient		
Spouse	46	23.5
Father	10	5.1
Mother	7	3.6
Sister	35	17.9
Brother	39	19.9
Child	46	23.5
Other	13	6.6
Employment		
Unemployed	86	43.9
Part time	71	36.2
Full time	24	12.2
Retired	10	5.1
Miss	5	2.6
Place of residence		
Urban	169	86.2
Rural	25	12.8
Miss	2	1
Education		
Elementary	69	35.2
Secondary	94	48
College	33	16.8
Age Mean	44.42±8.54	

Table 10. Characteristics of the patients

Statistics	N	%
Sex		
Female	56	28.6
Male	138	70.4
Miss	2	1
Education		
Elementary	94	48
Secondary	94	48
College	7	3.5
Miss	1	0.5
Marital status		
Married	63	32.1
Single	117	59.7
Divorced	8	4.1
Widow	6	3.1
Miss	2	1
Employment		
Unemployed	173	88.3
Part time	9	4.6
Retired	3	1.5
Early retired	10	5.1
Miss	1	0.5
Age Mean	39.49±11.47	
Type of illness		
Schizophrenia	120	61.2
BMD	47	24
MDD	29	14.8

The results of the second-factor analysis have shown in tables 11 and 12.

Table 11. KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		0.659
Bartlett's Test of Sphericity	Approx. Chi-Square	2497.477
	Df	210
	Sig.	0

Table12. Factor loadings for the seven extracted subscales after varimax rotation

	Component						
	1	2	3	4	5	6	7
q1	0.832						
q2	0.828						
q3	0.803						
q5	0.718						
q6	0.804						
q9			0.823				
q10			0.896				
q11			0.823				
q12				0.886			
q13				0.888			
q14				0.775			
q15						0.899	
q16						0.917	
q19		0.804					
q20		0.847					
q21		0.819					
q22							0.881
q23							0.839
q26					0.823		
q27					0.796		
q28					0.856		

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

Data were analyzed by principal component analysis with varimax rotation. Factor loading and residuals confirmed that a proper solution was chosen. Seven factors were found with eigenvalues of more than 1. Scree plot also confirmed these seven factors. The seven-factor structure that was mentioned above explained 78.45% of the total variance. The questions which resulted from the first factor analysis and were categorized in seven dimensions are mentioned below.

1) Emotional burden

Q1. Have you felt sad/depressed?

Q2. Have you felt exhausted?

Q3. Have you felt that you lack energy?

Q5. Have you felt helpless?

Q6. Have you felt hopeless?

2) Dealing with patient's symptoms

Q9. Have you been able to understand your patient's behavior?

Q10. Have you been able to manage bizarre and disruptive behaviors of your patient?

Q11. Have you had enough information about illness and process of treatment?

3) Relationship with therapeutic team

Q12. Have you been understood by doctors and nurses?

Q13. Have you been helped/supported by doctors and nurses?

Q14. Have you been satisfied with the information given by doctors and nurses?

4) Relationship with family

Q15. Have you been understood by your family?

Q16. Have you been helped/supported by your family?

5) Financial burden

Q19. Have you had financial difficulties in treating your family member's illness?

Q20. Have you had housing difficulties?

Q21. Have you had transportation difficulties?

6) Relationship with extended family and friends

Q22. Have you been understood by your extended family and friends?

Q23. Have you been helped/supported by your extended family and friends?

7) Latent worry

Q26. Are you worried about the possibility of leaving your patient independently without daily family support?

Q27. Are you worried about constant financial support for the living of your patient?

Q28. Are you worried about who should be in charge of your patient if you would no longer be able to support him/her?

4.3.3. Scoring

The mean of the item scores for each individual were computed to obtain a score for each of the dimensions. Item scores that have been worded negatively were reversed so that lower scores indicate a higher QoL.

Missing analysis was used to substitute missing items with the mean of non-missing items. A global QoL index was computed as the mean of the individual dimensions. In order to convert raw scores to transformed scores in all dimensions a 4-20 scale (the higher the score, the worse the QoL) was used.

4.3.4. Construct validity

Following face and content validity which is mentioned in chapter 3, principle component factor analysis was employed to form the structure of the questionnaire. In order to measure sample adequacy, Kaiser's criterion was applied (Table 11). Factor extraction was done based on eigenvalues more than 1. Finally, seven factors that explained 78.45 percent of the total variance were extracted.

These seven dimensions which were named according to their constituent items, comprised of 21 items (see appendix B), as follows:

EB: Emotional Burden (5 items);

DPS: Dealing with patient's symptoms (3 items);

RTT: Relationships with therapeutic team (3 items);

RF: Relationships with family (2 items);

FB: Financial burden (3 items);

RE_f F: Relationships with extended family and friends (2 items);

LW: Latent worries (3 items).

All factor loadings were in the acceptable range (0.718 to 0.917).

Item Internal Consistency (IIC) was satisfactory for all dimensions, ranging from 0.77 to 0.96 for each item. It indicates that each item should be highly correlated with its scale. Furthermore, items should be more highly correlated with their own scale than with other dimension scales (*Item Discriminant Validity*). Dimension scale characteristics are shown in table 13.

Table 13. Dimension scale characteristics of the 21- item final version of the SAC-QoL

SAC-QoL	IIC	IDV	MV	Floor	Ceiling	Cronbach's alpha	Mean (SD)
	Min-max	Min-max	(%)	(%)	(%)		
EB	0.77- 0.87	0.03- 0.31	2	1	1	0.88	12.32 (2.32)
DPS	0.82- 0.92	0.10- 0.39	0	1	9.2	0.87	15.14 (2.94)
RTT	0.83- 0.89	0.001- 0.27	0	2	2.5	0.83	11.72 (2.72)
RF	0.95- 0.96	0.03- 0.25	0	13.3	3	0.89	8.75 (3.16)
FB	0.83- 0.92	0.05- 0.50	0	2	42.9	0.85	17.22 (3.37)
RE_fF	0.88- 0.90	0.02- 0.27	0.5	1.5	3.6	0.74	13.12 (2.55)
LW	0.87- 0.92	0.003- 0.49	0	0.5	24.5	0.87	16.07 (3.17)
Index	Not applicable	Not applicable	2	0	1	0.76	13.53 (1.28)

MV: missing value
IIC: Item internal consistency
IDV: Item discriminant validity

4.3.5. Reliability

Cronbach's alpha coefficient was computed to explore reliability for each dimension scale and for the global index. Internal consistency reliability ranged from 0.74 to 0.89, indicating high internal consistency in the whole sample. A Cronbach's alpha coefficient of at least 0.7 was expected for each scale.

4.3.6. Convergent validity

In order to explore other aspects of construct validity, dimensions and global score (index) of SAC-QoL were compared with WHOQoL-BREF dimensions.

The basic assumption was that dimension scores of SAC-QoL would be more correlated with similar dimensions of WHOQoL-BREF than the dissimilar dimensions. The SAC-QoL index was significantly correlated with all WHOQoL-BREF dimension scores (r=0.32- 0.65). Physical health dimension indicated medium to high correlation with EB and FB dimensions and low correlation with RTT, RF and LW dimensions. Psychological dimension showed medium to high correlation with EB and low correlation with RTT, FB, RE_fF and LW. Social relationship dimension only was weakly correlated with all dimensions of SAC-QoL except dimensions of DPS and FB. Environmental dimension showed high to medium correlation with EB, FB and LW and also had low correlation with DPS. The results are shown in table 14.

The basic assumption is confirmed by the results. It is demonstrated that environmental dimension is more highly related to the DPS, LW, FB and EB. It means that environmental dimension should include some items that have significant effect on coping with the patient's symptoms. As the items 8, 9, 12, 13, 14, 23, 24, 25 are the factors that facilitate coping process (see Appendix A), it is not surprising that they are more highly related to DPS, LW, EB and FB. Also, it is clear that EB is more related to psychological dimension rather than physical and social relationship dimensions. As the results show, social relationship is also more related to the similar dimensions of SAC-QoL than the dissimilar ones.

Table 14. Correlations between SAC- QoL scores and WHOQoL-BREF

	EB	DPS	RTT	FB	RF	RE_fF	LW
Physical health	0.48**	0.12	0.16*	0.42**	0.16*	0.1	0.28**
Psychological	0.51**	0.14	0.21**	0.38**	0.14	0.16*	0.32**
Social relationship	0.29**	0.04	0.17*	0.1	0.21**	0.34**	0.16*
Environmental	0.59**	0.38**	0.11	0.63**	0.01	0.006	0.45**

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

4.3.7. Divergent (discriminant) validity

In order to explore discriminant validity, comparison of known-group was applied. This method defined the questionnaire to some extent so that different groups and sub groups can be identified. It tests the relationships between SAC-QoL scores and socio-demographic variables as well as clinical features to explore the ability to discriminate respondents according to the pre-defined hypotheses. Three hypotheses were posed:

1) Caregiving duration is correlated with caregiver quality of life. Increase in caregiving duration may cause a decrease in caregiver quality of life.
2) Caregivers of individual with major depression disorder experience higher levels of QoL than caregivers of individuals with bipolar mood disorders or schizophrenia.
3) There is no difference between QoL of caregivers of schizophrenics and bipolar mood-disordered patients.

All dimensions of SAC-QoL and global index have positive relationships with caregiving duration, except for dimensions of RTT, FB and RE_fF (see table 15). As a higher score in SAC-QoL means lower quality of life, increase in caregiving duration leads to a decrease in caregiver quality of life. Thus, the first hypothesis was confirmed. Comparisons of patients' diseases (Schizophrenia, BMD and MDD) showed significant differences in all dimensions and global index except for dimensions of EB, RTT and RF. The analysis of variance (ANOVA) and Scheffe post hoc analysis indicated a significant difference in QoL of caregivers of MDD and two other disorders. Also, it showed that there is not any difference between caregivers of patients with schizophrenia and BMD in terms of quality of life and caregivers of patients with MDD have better quality of life than the other two disorders, thus the second and third hypotheses were confirmed.

The results of student's t-test and ANOVA showed no significant difference between male and female in any dimension of SAC-QoL. Educated caregivers had higher QoL in dimensions of DPS and FB. Conversely, they experienced lower QoL in dimensions of RF and RE_fF. Caregivers who lived in rural areas perceived higher QoL in dimension of DPS and FB and lower QoL in the RF dimension. There is not any difference between employed and unemployed caregivers in terms of QoL except for EB dimension in which caregivers perceived lower emotional burden. Four SAC-QoL dimension scores (EB, DPS, FB, LW) had significant positive correlations with the age of the caregiver which means QoL decreases as the age increases.

Table 15. Comparisons (mean±SD) and correlations (r) of SAC-QoL scores according to caregiver characteristics and patient illness

	EB	DPS	RTT	RF	FB	RE_fF	LW	Index
Gender of caregiver								
Female	12.38(2.14)	15.19(2.90)	11.64(2.61)	8.68(3.03)	17.37(3.16)	13.02(2.45)	16.17(3.08)	13.53(1.20)
Male	12.07(3.00)	14.85(3.16)	12.07(3.22)	9.11(3.75)	16.48(4.16)	13.50(2.96)	15.67(3.58)	13.51(1.60)
P value	0.565	0.53	0.389	0.522	0.232	0.315	0.441	0.935
t	0.57	0.63	0.86	0.73	1.21	1	0.85	0.68
Education								
Elementary	12.57(1.70)	16.08(2.55)	12.06(2.50)	8.20(2.40)	17.89(2.57)	12.72(1.90)	16.63(2.35)	13.74(0.99)
Secondary	12.22(2.51)	15.32(2.71)	11.47(2.69)	8.57(2.82)	17.30(3.32)	13.06(2.17)	15.88(3.26)	13.47(1.07)
College	12.05(2.83)	12.64(3.00)	11.72(3.23)	10.42(4.68)	15.60(4.39)	14.18(4.14)	15.45(4.18)	13.25(2.10)
P value	0.487	**0**	0.404	**0.003**	**0.005**	**0.025**	0.15	0.17
F	0.72	18.29	0.91	6.09	5.48	3.75	1.91	1.78
Residence								
Urban	12.38(2.31)	15.39(2.80)	11.78(2.72)	8.45(2.78)	17.67(2.82)	13.20(2.50)	16.18(2.91)	13.60(1.21)
Rural	11.93(2.45)	13.49(3.47)	11.36(2.83)	10.64(4.71)	14.19(4.99)	12.56(2.86)	15.17(4.55)	12.99(1.67)
P value	0.388	**0.014**	0.476	**0.032**	**0.002**	0.242	0.29	0.104
t	0.86	2.61	0.71	2.26	3.41	1.17	1.08	2.14
Type of illness								
BMD	12.08(2.18)	14.64(3.39)	12.23(2.96)	9.06(3.41)	17.62(3.44)	13.49(2.59)	16.72(2.89)	13.70(1.43)
SCHIZO	12.50(2.37)	15.74(2.33)	11.42(2.54)	8.53(2.66)	17.72(2.76)	12.78(2.17)	16.70(2.74)	13.63(1.12)
MDD	11.84(2.28)	13.42(3.63)	12.14(2.97)	9.17(4.45)	14.53(4.30)	14.00(3.61)	12.44(2.88)	12.79(1.48)
P value	0.313	**0**	0.153	0.465	**0**	**0.04**	**0**	**0.006**
F	1.16	8.79	1.89	0.76	12.16	3.27	28.78	5.3
Employment								
Unemployed	12.72(2.10)	15.21(3.07)	11.99(2.68)	8.98(3.49)	17.04(3.37)	13.19(2.42)	16.28(3.14)	13.70(1.24)
Employed	11.85(2.45)	15.06(2.87)	11.49(2.80)	8.44(2.82)	17.35(3.93)	13.13(2.74)	15.85(3.25)	13.35(1.31)
P value	**0.01**	0.73	0.217	0.244	0.535	0.873	0.351	0.058
t	2.59	0.34	1.24	1.16	0.62	0.15	0.93	1.9
Caregiving duration (r)	0.17^{*}	0.159^{*}	0.022	0.148^{*}	0.067	-0.049	0.174^{*}	0.162^{*}
Caregiver age (r)	0.227^{**}	0.227^{**}	0.032	-0.07	0.197^{**}	-0.036	0.221^{**}	0.205^{**}

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

4.4. Results of qualitative supplementary phase

Based on the exploratory and quantitative phases of the study, some of the main aspects of quality of life among caregivers of individuals with schizophrenia and affective disorders were detected. In order to explore such factors more profoundly, a supplementary phase was conducted. The average age of the caregivers was 45.17 years (18-75) and 12 (66.7%) of the sample were females. Our sample included 8 (44.5%) patients with schizophrenia, 7 (38.9%) patients with BMD and 3 (16.6%)

patients with MDD. The average age of patients was 41.2 years (20-63) and 13 (72.2%) of the sample were male. Demographic characteristics of the caregivers and their patients are shown in tables 16 and 17, respectively. As was described in chapter three, grounded theory was used for analyzing data. Accordingly, caregiving experiences can be summarized as follows:

Table 16. Characteristics of the caregivers

	n	%
N	18	100
Gender		
Female	12	66.7
Male	6	33.3
Age	45.17 years	
Marital status		
Married	11	61.1
Single	7	38.9
Relationship: caregiver is patient's		
Spouse	4	22.2
Parent	6	33.3
Child	3	16.7
Siblings	4	22.2
Other	1	5.6
Education		
Primary	6	33.3
Secondary	4	22.2
College	8	44.5
Residence		
City	14	77.8
Countryside	4	22.2
Income status		
high income	2	11.1
Ordinary	10	55.6
low income	6	33.3
Profession		
Dependent	9	50
Independent	9	50
Type of illness		
Schizophrenia	8	44.5
BMD	7	38.9
MDD	3	16.6

Table 17. Characteristics of the patients

	n	%
N	18	100
Gender		
Female	5	27.8
Male	13	72.2
Age	41.22 years	
Duration of illness	8.97 years	
Marital status		
Married	7	38.9
Single	11	61.1
Employment		
Employed	4	22.2
unemployed/ retired	14	77.8
Education		
Primary	8	44.4
Secondary	9	50
College	1	5.6
Residence		
City	14	77.8
Countryside	4	22.2

Caregiving experience of a mental illness is a trajectory that initiates from the *family system* and terminates to the family system or *institutional take care system*. At the onset of the illness, caregivers experience a kind of insecurity which is named *insecurity on the onset.* At this stage, caregivers do not know if it is a serious illness or a casual event. Thus, they do not feel any need to refer to a professional help. Nonetheless, they have the sensation that something is wrong with their kin so that they feel a certain latent worry. This insecurity exists along with a hope that the

irritations would disappear without any intervention. The female caregiver Nr. 7, table 19, expressed her initial feeling about her father´s illness: “Initially we did not know anything. We felt that he has changed through his behaviors and signs…. We gave hope to ourselves that maybe he will improve...” [Transcript, p: 35, line 13-14, 26]. When the illness enters a critical phase, they start *seeking cautious support* because of the felt stigma towards mental illness. *Seeking professional support* is the next phase that the caregivers experience in order to get a diagnosis and consequently, treatment. In the hospitalization phase of the patient, caregivers initially resist which is named *resisting a hospitalization.* It is also mainly due to a felt stigma. In the return phase of illness, the caregivers feel *increased responsibility.* They try to follow the orders of the specialists and pay attention to the patient more than before in order to provide the best recovery. In the backlash and chronicity phases of the illness, caregivers perceive some needs which is named *perceived needs* stage. Based on the coping strategies that caregivers adopt in this stage, they enter to the *exhaustion* or *unending care* phases. These strategies will be explained in the following paragraphs.

Table 18. The matrix presenting focused codes, sub-categories, and main categories

Main categories	**Sub-categories**	**Name of the codes**	**Anchoring examples**	**Properties**
Family-centered worries	Debilitative family relations	experiencing family conflicts	The male caregiver Nr. 18, table 19. "My wife and my daughters have conflict with the patient permanently. They cannot endure living with my sister in one place thus my sister should leave us because my life is being damaged…" [Transcript, p: 98, line 17-18].	Having children who live with the patient in the same place, taking care of patients with schizophrenia or BMD
		complaining impressionability	The female caregiver Nr. 15, table 19. “My son could not study because of my husband´s behavior. Thus, my son has lived in his friend´s home for two years…." [Transcript, p: 77, line 21-22].	Having children who live with the patient in the same place, taking care of patients with schizophrenia or BMD, caregiving duration

	Patient-centered concerns	feeling insecure	The female caregiver Nr. 2, Table 19. "I cannot go anywhere and leave him alone at home because he either goes out to search for methamphetamine (a narcotic) or does unexpected disruptive behavior" [transcript, p: 10, line 20-22].	Taking care of patients with schizophrenia or BMD, being older
		encountering financial difficulties	The female caregiver Nr. 2, Table 19. "He reduced me to the zero financially. He should take two or three tablets per day and it is so expensive to pay for…." [Transcript, p: 10, line 6-8].	Low income, poor governmental support, number of family members
		Feeling suspension	The female caregiver Nr. 1, table 19. "I do not know what I should do. His doctor told me if he marries, he may get better. But I have doubt about that because he had a failure in his previous marriage and I am afraid of the next marriage" [transcript, p: 3, line 4-6]. The male caregiver Nr. 4, table 19. "Sometimes I think that I have made a mistake because I have left my wife and children in a small city to take care of my mother. I am worried about it, maybe it hurts my own life. Maybe they are my first priority" [Transcript, p: 23, line 26-28].	Having parent or child kinship
		Foreseeing tenuous future	The female caregiver Nr.1, table 19. "If the conditions proceed like this, it will be a great tragedy because I am becoming decrepit and every one lives for himself/herself. There is no one else to take care of him" [transcript, p: 3, line 27-30].	Getting older
Society-centered worries	Stigma	feeling stigmatized	The female caregiver Nr. 7, table 19. "When I came to the hospital for the first time, I was afraid that someone might see me here because people may look at me in a different way. Maybe I seem to them to be unworthy and with a weak personality. I have always had such a feeling" [transcript, p: 38, line 14-16].	Having female patients, having parent or child kinship, having higher social prestige
	Governmental inadequacy	complaining governmental deficiencies	The female caregiver Nr. 3, table 19. "Mental medicines are so expensive and insurance does not cover the costs of medicine and it is not sufficient for the costs of visit and hospitalization" [transcript, p: 17, line 22-23]. The female caregiver Nr. 17,	Approximately all caregivers

			table 19. “The hospital situation is not fit for the patients. There is not enough staff and health care services to fit the number of patients. A lot of patients are in one room and different types of patients are hospitalized in the same ward. Patients with better states are mixed with those with worse states. There is no large and green space for the patients and they lack entertainment, enjoyment and enough outing” [transcript, p: 93, line 2-5].	
	Defective Social relations	complaining professional	The female caregiver Nr. 3, table 19. “Whenever we visit the doctor, the doctor does not speak with us … He only prescribes a medicine and tells me if he does not get better, take him to the hospital and he does not tell me anything else” [transcript, p: 17, line 6-8]. The male caregiver Nr. 12, table 19. “Some doctors see the patients just like money… our time and costs are not important for them and we have to come again and again and again. They see just the money” [transcript, p: 59, line 26-30].	Living in the city
		lacking social support	The female caregiver Nr. 16, table 19. “All people feel relaxed while he is by me, all of them are engaged with their own life. they do not call me at all to enquire about his state or offer me to take care of him at least for a week ….[transcript, p: 85, line 26-28].	Most caregivers lack social support
Coping strategies	patient´s symptom management	expecting self-control	The female caregiver Nr. 1, table 19. “When he behaved annoyingly, I warned him about the consequences of his behavior and advised him to change his behavior because I could not bear his odd behaviors” [transcript, p: 1, line 10-13].	Useless strategy
		doing attributional actions	The female caregiver Nr. 1, table 19. “Since his wife passed away, he has felt depressed….I tried to find a wife for him….” [Transcript, p: 1, line 1-4 and 26-27]. The male caregiver Nr. 6, table 19. “Somebody told me that Jinn has entered her body and you should expel it from her body…	

			We referred to the fortuneteller to expel the Jinn" [transcript, p: 34, line 24-27].	
		increasing awareness	The male caregiver Nr 4, table 19. "I have studied a lot in the field of psychology and these topics…. The problem has a genetic base… and to some extent our living environment may also affect forming the problem…." [Transcript, p: 19, line 5-6 and 18-19].	Useful strategy
		seeking professional support	The male caregiver Nr. 18, table 19. "When she got up in the morning, I did not know what had happened for her at sleep, she was in a bad mood. Thus, we took her to a doctor and told him that she has a problem…." [Transcript, p: 97, line 7-9].	All caregivers
		getting entrusted support	The female caregiver Nr. 8, table 19. "I have two son and one daughter….my sons have a good situation. They take and bring their sister and do some of her tasks…. take medicine for her ….they are so nice…." [Transcript, p: 41, line 16-19].	Useful strategy Living in a countryside
		getting periodic support	The caregiver Nr. 10, table 19. "I do everything for him [his uncle]…. sometimes her sisters take care of him, he has four aunts and they also take care of him…. [Transcript, p: 46-47, line 29 and 2-3].	Useful strategy Living in a countryside
		being hopeful	The male caregiver Nr. 12, table 19. "I am hopeful about the future. I hope my son will improve and then, at that light future, we will feel good too" [transcript, p: 59, line 1-6]. The female caregiver Nr. 15, table 19. "I am only hopeful that whatever I gave my kindness to the patient, God will give me a favor and my children's future will get better" [transcript, p:81, line 11-13].	Useful strategy

	Stigma management	concealing the illness	The female caregiver Nr. 5, table19. "The first days that he was hospitalized here nobody learned about that. I liked to conceal it…. because I think here has a bad reputation…. if we say psychiatric hospital everybody will look at us in a different way… [Transcript, p: 29, line 5-9].	useless strategy, having higher social prestige, having MDD patient
		Applying for social presentation of the patient	The female caregiver Nr. 17, table 19. "I apply for a job for her to go out in the morning in the society and come back afternoon… I think if she has a job and becomes busy… she will be cured… [Transcript, p: 95, line 12-23].	Useful strategy
		justifying oneself	The male caregiver Nr. 12, table 19. "Stigma exists for everyone who is hospitalized here…. It is important that he would be cured; this is more important than stigma…" [Transcript, p: 59, line 17-21].	Useful strategy
		informing	The female caregiver Nr. 17, table 19. "Some people ask me what happened to your daughter and I explained them she is ill and is now under treatment" [transcript, p: 94, line 22-23].	Useful strategy
		expressing family fame	The female caregiver Nr. 17, table 19. "We are a famous family and everybody in this city knows us... I have six children… they are healthy and rich. Only she has problem…. [Transcript, p: 90, line 12-18].	Having higher social prestige
	Hoping for compensation	protesting, suggesting, notifying, warning and pulling string towards authorities	The male caregiver Nr.18, table 19. "Admission process in the hospital takes a long time, sometimes it takes more than 3 hours. Thus, I pull strings to do the admission process faster" [transcript, p: 97, line 23-25].	Living in the city, having higher education

Table 19. Number-based identification system of eighteen interviewed caregivers and their characteristics

caregiver / characteristics	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
patient age (year)	40	33	55	54	45	48	59	45	39	40	27	20	40	33	63	32	38	31
patient gender	male	male	male	female	male	female	male	female	male	male	male	male	male	male	male	male	female	female
patient illness	BMD	schizo	BMD	MDD	MDD	schizo	MDD	schizo	BMD	schizo	schizo	schizo	BMD	BMD	schizo	BMD	BMD	schizo
caregiver age (year)	64	56	35	30	19	53	26	75	37	24	58	53	45	35	53	50	65	36
caregiver gender	female	female	female	male	female	male	female	female	female	male	male	male	female	female	female	female	female	male
caregiver states	mother	mother	spouse	child	child	spouse	child	mother	sister	nephew	father	father	sister	spouse	spouse	sister	mother	brother
caregiving duration	8	6	17	7	1	20	1	35	2	5	2	3	1	6	26	1	4	10
number of family members	3	4	4	5	3	3	5	2	3	3	5	4	3	2	5	5	2	5
caregiver education	primary	primary	primary	college	secondary	secondary	college	primary	college	secondary	primary	college	college	college	primary	college	secondary	college
caregiver residence	countryside	city	city	city	city	city	city	countryside	city	countryside	city	city	city	countryside	city	city	city	city
caregiver income	ordinary	low income	low income	ordinary	ordinary	ordinary	ordinary	ordinary	ordinary	ordinary	low income	ordinary	ordinary	low income	low income	ordinary	high income	high income

4.4.1. Family system

Family system was described as the main context in which caregiving experience took place. In examining data for context, what the concept of *family system* consists of is explored. Additionally, the relationship between family system as the main context of caregiving experience and its core concept will be demonstrated.

Family system consists of a combination of family members including patient and caregiver with or without other family members who live with each other with a special *family background*, *unmet and perceived needs, worries and coping strategies.*

There are two family systems including those of before and after using the therapeutic system with different needs, worries and coping strategies. After thinking a lot about the central concept of experience of caregiving for the mentally-

ill patients, we found that the main burden which has the most prominent effect on the quality of life is "one of worry". It is here called *"constantly latent worries"*. Approximately all caregivers experienced a kind of worry from the beginning of this experience. Here it is divided into two main categories: *family-centered worries* and *society-centered worries.*

4.4.1.1. Constantly latent worries

Family-centered worries

Family-centered worries included both worries about *relationship* such as worries about conflict between patient and other family members, effect of illness on other family members or on the caregiver, and also *worries about patient and its illness* including improvement or deterioration of illness, effectiveness of medicine and its side effects, unexpected happening or behavior by patient, worries about independency and worries about financial security of patient. When the caregivers are in the initial stages of their caregiving experience, they are more worried about *patient and his/her illness* than the *relations*.

The female caregiver Nr. 17, table 19, expressed her concern about unpredictable actions of her daughter: *"I am worried that she may commit suicide or may get up suddenly at midnight and go out or may bring someone at home. I am always concerned about these issues while I have two servants in my house. Not only me but also every other mother would think like me. Despite having two servants, I cannot go everywhere. I stay with the two servants at home. I do not dare to leave her at her home alone…."* [Transcript, p: 91, line 22-25].

The female caregiver Nr. 15, table 19, stated his concern about the effects of illness on another family member: *“my son could not study because of my husband´s behavior. Thus, my son has lived in his friend´s home for two years…." [Transcript, p: 77, line 21-22].*

Caregivers who had poor family relationships felt alone and helpless. Some of the properties of family system that have the most important effects on recurrence to the therapeutic system or take care system after hospitalization include family relationships, family resources, perceived needs and living with other family members.

The most constantly latent worries after hospitalization and probably chronicity of the illness in the family system are effectiveness and side effects of medicines, the probability of improvement, effect of illness on other family members, probability of self-subsistence and financial support of the patient, life independency, unpredictable actions or behaviors of the patient and who may take care of the patient in the absence of the current caregiver?

The female caregiver Nr.1, table 19, declared her concern about ongoing caregiving: *“if the conditions proceed like this, it will be a great tragedy because I am becoming decrepit and every one lives for himself/herself. There is no one else to take care of him”* [transcript, p: 3, line 27-30].

A female caregiver Nr. 13, table 19, expressed her concern about self-subsistence and financial status of her brother: *“my big problem is that he does not go to work…. He was an expert carpenter. After he became ill, he could not go to work and he is completely dependent on me. I should provide all of his needs. How long can I support him financially? He should improve and go back to his work to supply his*

needs by his own…. We have some heritages from our father but how long can we use it? Ultimately it will be finished… My big concern is that he can go back to work again" [transcript, p: 66 and 67, lines 9-12, 9-10].

Society-centered worries

Society-centered worries can be differentiated as felt and really lived experience of *stigma*, *governmental inadequacy i.e.* lack of local psychiatric facilities *and defective social relations i.e.* lack of social support or professionally.

Stigma towards mental illnesses is one of the main worries of caregivers and patients. Governmental inadequacy and defective social relations are two more sub-categories of society-centered worries which emerge more intensely when caregivers refer to the therapeutic system and come back to the family system. Both difficulties can put a main burden on the shoulders of family caregivers and consequently it can decrease quality of life. In the following *stigma* with regard to the family background would be explained. The *governmental inadequacy and defective social relations* are also explained in the section dealing with the therapeutic system.

Table 20. Core concept, primary categories, and sub-categories of caregiving experience

core concept	primary categories	sub- categories
		patient's- centered concerns
	family- centered worries	debilitative family relations
constantly latent worry		
	society- centered worries	stigma
		governmental inadequacy
		defective social relations

From the beginning of caregiving experience and during a period of time, based on the properties of family or therapeutic system, there is a change in the type and amount of worries as well as coping strategies. In the following, the family and therapeutic systems alongside their properties including family background, special worries of each system and the main contributing factors will be explained; additionally, the methods that caregivers adopt to manage their worries will be illustrated.

Family background

Family background, as a primary property of *family system,* plays a main role to show how and to what extent caregivers experience different kinds of worries. It included family resources, number of family members, social class, patient's gender, kinship with the patient, illness severity and relations.

Society-centered worries are more prominent when that patient is female. The female caregiver Nr. 17, table 19, stated, *"I do not dare to permit her to go out alone because someone may deceive her and make love with her and then quit her".* [Transcript, p: 94, line 14-16].

This issue pointed at the gender discrimination as a result of stigma because here there is a female patient. In our culture we do not have such problems when the patient is male. Also some participants who took care of female patients stated such problems. The male caregiver Nr. 18, table 19, acknowledged, *"When my sister escapes from our house I must look for her immediately because it is a big social*

problem and if the neighbors learn about it, they will gossip about my sister" [transcript, p: 97, line 18-20].

Analysis of data showed that child and parent kinship between caregiver and patient, especially when the caregiver is the parent and patient is the child, is more related to society-centered worries. They try to conceal the problem and do attributional actions to manage the problem. The male caregiver Nr. 12, table 19, explained, *"We conceal the hospitalization of our son because if someone learns about it, nobody will marry him and it will have a bad effect on his future life"* [transcript, p: 59, line 14-18].

In families with higher social class and lower symptom severity, there is more intention to conceal in order to avoid stigma. Also some caregivers prefer to avoid accompanying their patients in social situations because of feelings of shame and embarrassment. The male caregiver Nr. 18, table 19, declared: *"as far as possible, I do not take my sister with myself at parties because she does some behaviors that make me ashamed"* [transcript, p: 98-99, line 28-29 and 1-2].

The results of our study show that when the family has higher social class, the patient is female and the type of kinship is child and parent, the society-centered worries would increase. On the other hand, in a family system with more family members, confined resources and restricted relationships, the family-centered worries increase.

4.4.1.2. Coping strategies

In the initial stages of caregiving, when caregivers see the first symptoms of their patient, they adopt some strategies to manage family-centered or society-centered

worries. These strategies are active/interactive or emotional responses to overcome different kinds of worries. These strategies are here called *patient's symptom management* and *stigma management*. One of the first strategies that caregivers used as the sub-category of *patient's symptom management*, is called *"self-control expectation strategy"*. According to this strategy, caregivers expect from their patient to control their annoying or odd behaviors and act in a normal way. For achieving this goal, caregivers apply some methods such as warning, notifying and advising. It is related to the onset phase of illness and it is not a useful strategy because it has originated from a kind of insecurity about illness. *The female caregiver Nr. 1, table 19,* remembered her first reactions versus patient's behaviors: *"When he behaved annoyingly, I used to warn him about the consequences of his behavior and advise him to change his behavior because I could not bear his odd behaviors" [transcript, p: 1, line 10-13].*

When the aforementioned strategies did not work, they use new strategies based on the reasons that they attributed to the problem. This strategy is named *"attributional actions strategy"*. Some caregivers assign some external stressors to the problem and try to resolve this stressors. For example, the female caregiver Nr. 1, table 19, explained: *"since his wife passed away, he has felt depressed….I tried to find a wife for him…." [Transcript, p: 1, line 1-4 and 26-27].*

Some caregivers related the problem to the genetic root as well as environmental factors and tried to ask for help from the relevant professionals. The male caregiver Nr.4, table 19, stated: *"This problem has a genetic root in my family. My grandfather and two of my uncles had the same problem…. Besides the genetic root, the tense atmosphere that my mother lives in is another reason for her problem"* [transcript, p:19, line 1-5].

Some other caregivers attributed the problem to some customs or religious beliefs. According to a religious belief some people have evil or energetic eyes and can injure others by their eyes. In this situation caregivers do some special customs and prayers related to the *evil eyes* hoping to remove the problem. Also, they might attribute the problem to the Jinn which has a religious root. The male caregiver Nr. 6, table 19, explained: *"somebody told me that the Jinn has entered into her body and you should expel it from her body….we referred to the fortuneteller to expel the Jinn" [transcript, p: 34, line 24-27].*

Although attributional action strategy works for some cases temporarily, it is not a useful strategy for all cases for a long term. Because most of the caregivers acknowledged that this strategy did not work for them to cope with the patient properly and some cases indicated that it had a reverse effect.

Also, some caregivers increase their knowledge about this situation by reading and studying and if they were not literate or highly educated, they try to learn by getting help and counsel from others that have a relative knowledge of this situation or have the same problem. It was a useful strategy as it was found out that caregivers who had more knowledge about the illness, regardless of the educational level or residence, could cope with the situation better than the others. The male caregiver Nr 4, table 19, stated: *"I have studied a lot in the field of psychology and about these issues…. The problem has a genetic base… and to some extent our living environment may also be effective in forming the problem…." [Transcript, p: 19, line 5-6 and 18-19].*

Caregivers had also society-centered worries at the beginning of caregiving experience. Main worries in this stage were related to stigma. Thus, their strategies

were oriented to *stigma management*. One of the most important and initial methods to manage stigma was *concealment*. Because of negative attitude of society about mental illness and consequences of disclosure, caregivers try to conceal their patient's illness as far as possible. Even they avoid to refer to professionals or psychiatric clinics because they were afraid that some extended family members learn about that. Usually, *concealment* is the first strategy of stigma management unless they are obliged to adopt another strategy, for example when the symptoms are severe, caregivers could not manage the stigma by using the *concealment* strategy. It means that in some cases (especially schizophrenia and BMD) because of symptom's severity (bizarre and aggressive behaviors), caregivers resort to some other strategies such as self-justifying, informing and expressing family fame to fade the stigma.

Because mental illness stigma is one of the main burdens of caregivers, the first stigma management strategy is concealment, especially when the family has a high social class or the illness and its symptoms have lower severity. Also, parental kinship between caregiver and patient increases the worries especially society-centered worries. Concealment is also a useless strategy because it causes the caregivers to refrain from seeking professional help. This occurs especially for caregivers of people with major depression disorders and caregivers with higher social prestige. When the aforementioned strategies did not work, caregivers feel an obligation to refer to the therapeutic system.

There are also some coping strategies that caregivers apply in the family system after discharge of their patient from the hospital. They need family or extended family support and also governmental and welfare facilities. Family support is a key factor in decreasing burden and promoting quality of life. Two main coping

strategies in the backlash or chronicity phases of the illness are *entrusted support* (entrusting some responsibilities of caregiving to the other family members or extended family; in fact it is a kind of labor division that helps caregivers to cope with the patient easier), and *periodic support* (all responsibilities of the patient are up to a caregiver for a specific period and then they are shifted to another caregiver in the family or extended family and also in some cases it can be shifted to a governmental caregiver as some caregivers in our study asked the government for this kind of caregiving). Getting entrusted or periodic support are useful strategies that help caregivers to cope with the illness. These strategies emerge especially among caregivers who live in countryside.

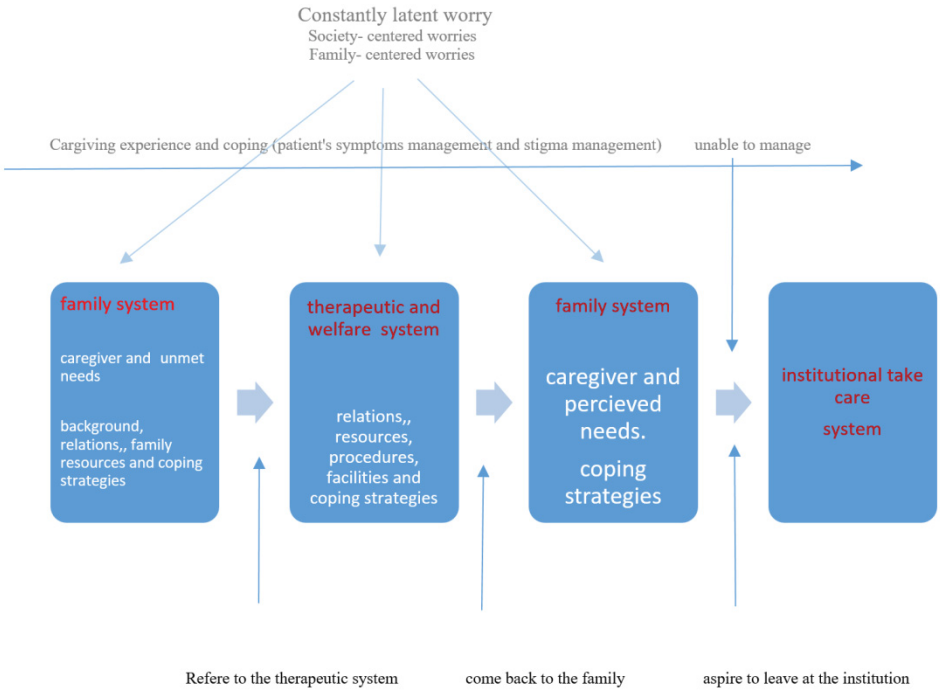
Coming back to the family system after hospitalization has its own special characteristics. Parent caregivers as well as caregivers with high social class prefer to apply concealment strategy because of fear or anxiety of losing acknowledgment and status or because of stigmatization. Therefore, they feel isolated. One of the useful strategies that caregivers apply to cope with the society-centered worries is *promotion of social presentation of the patient* (preparing the patient for presenting him/her in the society by means of giving insight to the patient about political and cultural conditions of the society and seeking a fit and confident job for him/her. In fact caregivers want to promote the presence of their patient in the society to decrease their worries about interactions of patient with the society). The female caregiver Nr. 17, table 19, stated her idea about social presentation of her patient: “I apply for a job for her to go out in the morning to the society and come back afternoon… I think if she has a job and becomes busy… she will be cured… [Transcript, p: 95, line 12-23].

Another strategy that helps caregivers to cope with the patient and his/her illness is *being hopeful.* This strategy has two aspects; one aspect is to *hope for future* and another is *being hopeful to the God's favor and reward.*

Hope for future is aspiring future improvement in the patient's states and symptoms. Caregivers who remained hopeful try to find better specialists and new medicines and sought professional supports in order to promote patient's state. Despite a long period of caregiving, some caregivers are still hopeful for the future and about the improvement of the patient. This encourages caregivers to pursue the treatment process more seriously and precisely and they do not feel frustrated during a prolonged caregiving period. It seems that it is one of the most efficient coping strategies, especially in case of severe mental illnesses such as schizophrenia. The male caregiver Nr. 12, table 19, expressed his aspiration about the future despite frequent referrals to different clinics and specialist: *"I am hopeful about the future. I hope my son will improve and then, at that light future, we feel better too"* [transcript, p: 59, line 1-6].

Some caregivers explained that they endure difficulties of caregiving because they have faith in God who helps and rewards them elsewhere. The female caregiver Nr. 15, table 19, explained her conditions: *"I am only hopeful that whatever I gave my kindness to the patient, God will give me a favor and my children's future will get better"* [transcript, p:81, line 11-13].

Figure 2. Diagram of worries as the core concept and trajectory of coping strategies



4.4.2. Therapeutic and welfare system

It includes a combination of therapeutic specialist, counselors, rehabilitation specialist, nurses and other staffs at the outpatient or inpatient clinics or hospitals. Also, welfare system includes some types of financial or caring supports. Results of this study show that therapeutic system was referred to when caregivers cannot manage patient's symptoms by using *self-control expectation* strategy or *attributional action* strategy. Thus, they were obliged to ask for help from therapeutic system. Therapeutic system has also some properties that influence the caregiving experience. It included family background as was mentioned in family system, relations, worries and coping strategies.

Family background

Worries experienced by caregivers may be related to factors such as social class, residence, illness severity and family resource. Families with high social class were more concerned with society-centered worries. They were extremely worried about both stigma, especially stigma related to hospitalization, and defective social relations because the expectation level from caregivers with high social class is more than those who are less educated or live in rural areas. The female caregiver Nr. 7, table 19, expressed her felt stigma related to the hospitalization: "when I came to the hospital for the first time, I was afraid that someone might see me here because people may look at me in a different way. May be I seem to them to be unworthy and with a weak personality. Always I have had such a feeling" [transcript, p: 38, line 14-16].

Caregivers who lived in rural areas had additional problems in the hospitalization stage because of lack of suitable therapeutic facilities and proper transportation to

the hospital. The caregiver Nr. 10, table 19, who lived in the countryside explained, *"In our region, we do not have a good doctor… Here I saw about ten patients from our region. If a doctor could visit patients in our region it was so good… We cannot bring our patients here. It is so hard for us….Here is far from the countryside… It annoys me a lot"* [Transcript, p: 47, line 4 and 9-12].

Caregivers who lived in city also had their own problems regarding hospitalization of their patient. The caregiver Nr. 15, table 19, stated, *"We should bring the patient here with a handcuff. Whenever I want to hospitalize my patient, I have to go to the police station and then I should go to the court to give me a letter so that the police can come to my house and catch the patient and take him to the hospital"* [Transcript, p: 76, line 14-16].

4.4.2.1 Constantly latent worries

The main worry in the hospitalization stage is *stigma*. Because of worries about stigma, referring to the therapeutic system took place with caution. Most caregivers were worried about stigmatization especially stigma related to hospitalization. Thus they resist hospitalization. When caregivers felt unable to manage patient's symptoms, they preferred to ask help and support from the therapeutic system.

The sub-categories of society-centered worries are stigma, governmental inadequacy and defective social relations. These worries emerge mostly when the caregivers refer to the therapeutic system. It includes a variety of difficulties such as difficulties related to the provision of medicine, cost of therapeutic system, insufficient insurance cover, lack of supportive policies, difficulties related to distribution of welfare and therapeutic facilities and transportation difficulties. The

female caregiver Nr. 3, table 19, who had some complaints about governmental deficiency expressed, “Mental medications are so expensive and insurance does not cover the costs of medicine and it is not sufficient even for the costs of visits and hospitalization” [transcript, p: 17, line 22-23].

The female caregiver Nr. 17, table 19, declared her complaints: “The hospital’s space is not sufficient for the patients. There is not enough staff and health care services to fit the number of patients. A lot of patients are in one room and different types of patients are hospitalized in the same ward. Patients with better states are mixed with those with a worse state. There is no large and green space for the patients and they lack entertainment, enjoyment and enough outing” [transcript, p: 93, line 2-5].

4.4.2.2. Coping strategies

When caregivers refer to the therapeutic system, the first strategies to manage stigma are *concealment* and *self-justifying.* Alongside the concealment strategy, some caregivers prefer to justify themselves that the improvement has precedence over everything. The male caregiver Nr. 12, table 19, stated, “Stigma exists for everyone who is hospitalized here….It is important that he will be cured. This is more important than stigma…” [Transcript, p: 59, line 17-21].

When patient’s illness is disclosed among the extended family and friends, caregivers change their strategy and apply some other strategies such as informing and expressing family fame. Some caregivers try to explain the illness and treatment process to others and give them some information about the patient when they encounter an annoying situation in the society. The female caregiver Nr. 17, table 19, acknowledged, “some people ask me what happened to your daughter

and I explained that she is ill and now is under treatment" [transcript, p: 94, line 22-23].

In families with a high social class, especially in terms of family fame, reputation and fortune, caregivers try to express family fame to fade the impact of stigma. The female caregiver Nr. 17, table 19, stated, *"We are a famous family and everybody in this city knows us... I have six children… they are all healthy and rich. Only she has problem…* [Transcript, p: 90, line 12-18].

Protesting, suggesting, notifying, warning and pulling string are the strategies that the caregivers resort to, to cope with the inadequacy of therapeutic system. In fact, these strategies are related to the governmental inadequacy or defective social relations. We categorized these strategies under a higher level category which is named *"hoping for compensation"*. The male caregiver Nr.18, table 19, expressed how he conquered governmental deficiency: *"Admission process in the hospital takes a long time, sometimes it takes more than 3 hours. Thus, I pull strings to do admission process faster"* [transcript, p: 97, line 23-25].

Sometimes because of inadequacies in therapeutic system caregivers prefer to return their patient to the family system before the psychiatrist discharges him/her. The female caregiver Nr. 5, table 19, explained about the hospitalization of her father*: "While my father was hospitalized here I was so sad and I cried because I could not see my father in a place like this. Thus, after ten days I decided to discharge my father…"* [Transcript, p: 26, line 20-21].

Table21. Coping strategies of the caregivers

	Expecting self-control
	Doing attributional actions
	Increasing awareness
patient´s symptoms management	Seeking professional support
	Getting entrusted support
	Getting periodic support
	Being hopeful
	Concealing the illness
	Applying for social presentation of the patient
stigma management	Justifying oneself
	Informing
	Expressing family fame
hoping for compensation	Protesting, suggesting, notifying, warning towards authorities and pulling strings

4.4.3. Perceived needs

Lack of family resources, governmental and welfare facilities as well as inadequacies in therapeutic system resulted in some new worries by caregivers. In fact while coming back from the therapeutic system to the family system, most caregivers perceive some new needs. These *perceived needs* are associated with the *family and acquaintances support, therapeutic support and governmental support*. These worries were mostly related to providing costs of therapeutic services due to the high costs of medicine and treatment concerning mental illnesses and worries about therapeutic space and procedures as well as relations with the therapeutic staff. The female caregiver Nr. 3, table 19, complained about the psychiatrist. She explained,

"Whenever we go to the doctor, the doctor does not speak with us. For example, I explain to him how my patient behaves, does not take medicine, annoys me a lot, quarrels with me, swears at me and so on; he only prescribes a medicine and tell me if he does not get better, take him to the hospital and he does not tell me anything else" [transcript, p: 17, line 6-8].

The male caregiver Nr. 12, table 19, indicated his idea about some doctors: *"Some doctors have economic ideas about the patients. A couple of days ago I was in a taxi and the driver saw a person. He told there is a coin there. In fact he was seeing the human like a coin. Some doctors see the patients like money…. Every illness has a process and doctors know that and can explain it to the patient's family. Some of them tell me that there is no cure for these patients and some of them tell me such patients improve very well and fast…."* [Transcript, p: 59-60, line, 27-30 and 4-6].

The female caregiver Nr. 17, table 19, was dissatisfied with doctors and nurses and declared, *"I am not fond of doctors and nurses. They are not unanimous with the patient. They do not pay attention to the demands and needs of the patient. Does the patient want to see his/her family? What does she want to eat?....She told me that during the hospitalization in this hospital she has been hungry in the mornings and had nothing to eat until I had cooked and brought launch for her from home…. The nurses do not speak with patients properly. One day I saw a nurse talked to my patient aggressively to take lunch and eat it while she could not even get up".* [Transcript, p: 93-94 and 96, line 29, 1-3 and 17-19].

Generally, although referring to the therapeutic system initially decreases some worries about patient's symptoms, it can potentially increase some aspects of both society-centered and family-centered worries.

Coming back to the family system had its own special burdens which originated from *constantly latent worries*. *Society-centered worries* can be caused by *feeling alone* because it is directly related to *stigma.* Stigma prevents caregivers from seeking help and support from others and consequently it ends in *feeling alone. Feeling helplessness,* which emerged as one of the main burdens of caregivers in the quantitative phase of the study, resulted from society-centered worries. Also, caregivers who had a patient with severe symptoms experienced more family-centered worries and had more feelings of *hopelessness* and *exhaustion* than other caregivers. Feelings of *exhaustion*, *hopelessness* and *lack of energy* that appeared in the quantitative phase are more related to family-centered worries. Another feeling that the caregivers experienced after hospitalization was *feeling in suspension.* It was more related to the parent or child caregiving. Caregivers who worried about their child or parent felt *in suspension* because of receiving contradictory information about taking medicine, improvement, hospitalization, getting married and so on and have doubts about life priorities. The female caregiver Nr. 1, table 19, explained, “I do not know what I should do. His doctor told me if he marries, he may improve. But I have doubt about that because he had a failure in his previous marriage and I am afraid of next marriage” [transcript, p: 3, line 4-6].

The male caregiver Nr. 4, table 19, stated, “Sometimes I think that I have made a mistake because I have left my wife and children in a small city to take care of my mother. I am worried about it, maybe it hurts my own life. Maybe they are my first priority.” [Transcript, p: 23, line 26-28].

To sum up, caregivers who get help and support by periodic or entrusted caregiving, keep their hope, take care of the patient as the parent or child with lower severity of symptoms, have enough financial resources and do not live with other family

members can cope much better with the patient than other caregivers and intend to take care of their patient in the family system rather than in an institute. On the other hand, living with the patient and other family members in the same place, having poor relationship with the extended family and friends, not having parental kinship, having a patient with severe symptoms, frequent relapse and having low financial resources may more probably lead to leaving the patient in an institutional take care center.

4.5. Recommendations

Based on the results of this study, most caregivers bear different kinds of burdens especially burdens that have significant impact on QoL of the caregivers. Concerning both socio-demographic factors and some clinical characteristics of the patients, the authors have some recommendations for the government or health-care system, health-care professionals and also for caregivers.

Government and health-care system should pay more attention to the specific needs of family caregivers by supporting caregivers and their family members financially, improving insurance coverage regarding the cost of psychiatric medicine and hospitalization, providing suitable and standard therapeutic spaces as well as enough and trained specialist and staff in psychiatric wards. On the other hand, system should provide respite care through welfare organizations or insurance especially for the older caregivers who have patients with schizophrenia or BMD and live with their children and the patient in the same place. Furthermore, because having parental or child caregiving role is equal to more burden in some aspects, like feeling in suspension and stigmatized, authorities should increase the caregiver´s knowledge about nature of mental illness, treatment process and useful coping

strategies through educational workshops and the mass media. The media have an undeniable effect on public thoughts. It can promote morale of hope amongst caregivers and break the taboo of mental illness. Because stigma towards mental illness is a ubiquitous burden by the caregivers, government should focus on that by a coherent program. Government should also provide job opportunities for individuals with severe mental illness because it might help caregivers and their patients through increasing social presentation and independency of the patient as well as decreasing most worries of caregivers as is mentioned in the present study.

As is mentioned above, results indicate that most caregivers had financial complaint because of therapeutic costs. They pointed at the inadequacy in therapeutic and welfare system (pp: 103-104). Because in Iran the welfare organization has the most important responsibility regarding wellbeing of disabled persons and their families, it is recommended to the welfare organization to undertake the costs of health-care services, such as medicine and doctor´s visits, that are not under insurance coverage. Also, it is recommended to the politicians to enact laws which promote health and social insurance towards supporting family caregivers and their patients so that they would cover not only hospitalization expenses but also the costs of visits and medicines because psychiatric medicines are too expensive and the patients need frequent visits by the doctors in the process of treatment.

As was pointed out in coping strategies in the family system, entrusted and periodic supports as the main parts of respite care were very useful for caregivers to cope with their situation (p:99). Thus, apart from extended family, the government can support caregivers through respite care. It might be launched either through enacting new rules for insurance coverage of severe mental illnesses and their caregivers or by financial empowerment of welfare organization. Respite care can

help the relief or assistance of people with disabilities living in the community as well as their families for limited periods of time in planned or unplanned ways. This service could especially include caregivers of individuals with schizophrenia and bipolar mood disorders and also mother caregivers who endure much more burden than other kinds of kinship (p: 108). Concerning mother caregivers of severe mental illnesses, as the results show and according to the caregiver´s will, it would be better to render a planned respite care at home for short-time periods such as one or two days per week. With respect to other caregivers who do not have parental kinship, unplanned (in emergency or crisis time) respite care out of home for longer periods is recommended. It can be offered as day-care respite and holiday-respite especially where the patient is young, and/or as alternative to hospital care or crisis intervention.

Health-care professionals play an important role in QoL of caregivers. If they do their job properly, it can help caregivers to play their caregiving role in a more adaptive way. According to complaints of some caregivers about health-care professionals regarding a defective relation between them (table 18, P: 87), it is recommended to them to form a sincere and rational relationship with the caregiver and the patient, to increase the knowledge of caregivers about the illness and treatment process and to decrease the emotional burdens. Trustworthiness and sincerity are two main factors in shaping a helpful relationship between professionals and caregivers. Our results suggest professionals to listen to caregivers attentively in order to understand them. They should respect caregivers and patients and behave respectfully. Health-care professionals including general practitioners, psychiatrics, nurses, psychologist, rehabilitation specialists, social workers and so on should provide some specialized consultation hours for family caregivers not only to provide pure medical information about psychiatric diseases but also to train them

how to deal with the patient at home in everyday situations, how to deal with family conflicts due to the illness of a family member, how to organize public support by social workers or family nurses and so on. Moreover, because some caregivers, especially parent caregivers, feel in suspension about some patient´s affairs such as the process of treatment and routines, professionals should provide precise consultations to give a feeling of confidence to caregivers.

As the results show, most difficulties of caregivers are related to lack of adequate information about the illness and the way of coping with different problematic situations (pp: 91-97). Caregivers should get useful information about their ill relatives through confident experts. They need to increase their knowledge by counseling a specialist in order to learn how they can live with their patient in a better way. Thus, they can participate in educational courses or increase their awareness through studying different valid resources. It would be useful for caregivers to be engaged in social support groups. In these groups they can increase their information and boost their self-esteem through an exchange of information by individuals; this provides emotional and network support. Also, the caregivers can form some informal groups with other caregivers to exchange their information and share their experiences with each other in order to learn about and obtain useful coping strategies. It is suggested to family caregivers to stay active and engaged in community mental health programs through full collaboration with mental-health professionals. They need each other in a holistic way because they have the same goal. Family caregivers not only need to educate themselves, but also play their role in educating the public regarding mental illness, its effects, realities and wrong conceptions concerning it. Community mental health program is more accessible and effective than mental hospitals. It can lessen the impact of stigma

and social exclusion. Hence, it can facilitate the process of social integration among mentally ill individuals.

Results of this study indicate that being hopeful to the future and being religious and having faith in God could help caregivers to cope with the situation in a useful way (pp: 100-101). Thus, it is recommended to caregivers to keep their hope about new medicines and methods in treatment as well as about the improvement of the patient in the future. Also, they might participate in the religious rituals because it can calm them down through both praying and getting social support in the public.

Chapter5: Discussion and Conclusion

5.1. Introduction

The main results of three phases of the study are discussed in this chapter. Then, the limitations and conclusion of the study are presented.

5.2. The qualitative exploratory phase

Our study was based on problem focused, semi-structured interviews to investigate the burden of an Iranian sample of caregivers of patients with schizophrenia and affective disorders. It was conducted by experienced and trained researchers. The roles of the authors were clearly differentiated: medical staff selected the patients along the prescribed criteria. The interviewer played no role in the therapy process, nor was he a member of the clinical staff during the time of the study. The researchers were not involved either in the therapy of the patients or in the counseling of the caregivers. The field contact throughout the study was Dr. Eslami, one of the co-authors.

Our findings indicated that, despite some differences regarding perceived burden among caregivers of schizophrenia and affective disorders, a common pattern of burden could be identified. This is consistent with preceding studies (S Chakrabarti & Kulhara, 1999; Ganguly, Chadda, & Singh, 2010; Navab et al., 2013; Ali Navidian, Fatihe Kermansaravi, & Shahindokht Navabi Rigi, 2012b; Vasudeva, Sekhar, & Rao, 2013). As our study showed, emotional burdens were ubiquitous, which was in agreement with previous studies in Iran and other countries (Bhatia & Jena, 2011; Gater et al., 2014; Khodabakhshi-Koolaee, 2010; Knock et al., 2011; MALAKOUTI et al., 2003).

Most participants reported financial troubles, unawareness, incertitude, and stigma. Findings of other studies confirmed these burdens (Khodabakhshi-Koolaee, 2010; Sharif et al., 2012). Like our findings, financial burden has been repeatedly shown in studies as one of the primary burdens among caregivers of the mentally ill (Bhatia & Jena, 2011; Sandeep Grover et al., 2012; Wong et al., 2012). Because our sample had the maximum variety of demographic variables, its cause can be explained as a lack of help and support from extended family and friends, health services, and governmental support.

One of the most frequent burdens reported by caregivers was the unawareness of the nature of the illness, treatment schemes, or illness trajectories, all of which is in accordance with prior studies (Bauer et al., 2011; S Chakrabarti, Kulhara, & Verma, 1992; S. W.-c. Chan, 2011; Sharif et al., 2012; Wei, 2008). Inadequate information given by doctors and nurses, absence of educational support from health service centers, failure to actively seek information about illness, and possibilities of treatment by caregivers due to low literacy or specific cultural representations of psychiatric disorders can be hypothesized as the leading reasons for unawareness. In contemporaneous Iran culture, mental illness is widely considered a taboo and many caregivers are worried about stigma; as a result, they are not knowledgeable about their loved ones' illness and their respective needs.

Caregivers' worries were categorized under the term incertitude, which refers to the unpredictable nature of the future and the caregivers' ambivalence about illness and the treatment process. The majority of participants indicated their worries (see Table 3). The most frequent worries were related to the future, the possibility for the patient to become self-subsistent and live independently, and the caregiver's worries about future of other family members; these findings were consistent with

other studies (S. W.-c. Chan, 2011; Gater et al., 2014; Sandeep Grover et al., 2012; Knock et al., 2011; Martire et al., 2009; Ogilvie et al., 2005; Phelan, Bromet, & Link, 1998; Rose et al., 2006; Shah et al., 2010). According to the caregivers' statements, the main reason for worries about the future of other family members was related to courtesy stigma.

The process in which a person is stigmatized by virtue of his or her association with another stigmatized individual has been referred to as an “associative” or “courtesy” stigma (Link & Phelan, 2001). Stigma derives from culturally fixed social representations of mental illness and madness, as well as the respective stereotypes and prejudice, and often results in overt and non-overt forms of discrimination (Angermeyer, Schulze, & Dietrich, 2003; Penn et al., 1994). Several studies have proven that stigma has a great impact on caregivers of mentally ill relatives (Bauer et al., 2011; S. Chan & Yu, 2004; Sandeep Grover et al., 2012; Martens & Addington, 2001). According to our results, it also includes burdens related to use of professional help, which has a higher rank in caregivers of patients with MDD in comparison with two more groups (see Table 4). In the light of the concealed nature of MDD, caregivers experience stress and worry that others may learn about their relative's illness. This finding is consistent with a study that found a label of depression to elicit more negative assessments of a vignette subject’s skills than did a label of schizophrenia (Angermeyer, Link, & Majcher-Angermeyer, 1987; Penn et al., 1994). Also, a study reported that concealment was significantly higher among relatives of patients with less severe positive symptoms at baseline (Link & Phelan, 2001). Statements of participants showed that caregivers of MDD patients tried to avoid professional help for as long as possible because of stigma. The most significant problems related to stigma for caregivers of MDD patients relate to hospitalization. Indeed, psychiatric hospitalization, apart from type of diagnosis,

plays a critical role which agrees with the results of some other studies (Angermeyer et al., 2003; Link & Phelan, 2001). The majority of participants declared that hospitalization in a psychiatric clinic equals the stigma of “madness”. Also, some of them stated that hospitalization can tarnish their family's reputation and cause them to be blamed for the madness of their relative. Thus, culture is responsible for such attributions and the subsequent risks of social isolation.

Other themes, such as physical burden, disruption of routine and medication-related burden, have often been mentioned in previous studies, not only for mentally ill patients but also for physically ill and/or disabled people. Some studies declared that these themes have a lesser burdening effect in comparison to others. The present study confirms these findings (Gater et al., 2014; Sandeep Grover et al., 2012; Maji, Sood, Sagar, & Khandelwal, 2011; MALAKOUTI et al., 2003; Singh & Prajapati, 2012). On the contrary, some studies showed a high frequency in the aforementioned burdens (Knock et al., 2011; Rose et al., 2006). Moreover, our findings were similar to studies that highly stressed the extent of burden related to restriction in routines (Subho Chakrabarti, Raj, Kulhara, Avasthi, & Verma, 1995; Sandeep Grover et al., 2012; Maji et al., 2011; Singh & Prajapati, 2012). Most caregivers stated that they were not free and they had to decrease their relationships as well as their leisure activities.

Dissatisfaction with family, relatives, and acquaintances is one of the primary categories related to the relationships of caregivers with others (see Table 3). These relationships can significantly affect the amount of perceived burden in other areas; for example, help and support from extended family as well as friends and acquaintances can decrease the financial burden, and understanding by the family and acquaintances as well as satisfaction with the emotional and sexual life can

decrease the emotional burden of caregivers. Our results showed that caregivers generally received decreasing support from extended family and friends and, additionally, were confronted with many conflicts in everyday life, which aligns with the results of other studies (Bauer et al., 2011; Gater et al., 2014; Maji et al., 2011; MALAKOUTI et al., 2003).

Caregivers frequently mentioned troubles related to health services and governmental support. According to our results, this was one of the most important burdens among caregivers (Bauer et al., 2011; Chimeh et al., 2008; Gater et al., 2014; MALAKOUTI et al., 2003; Mansouri et al., 2013a; Mansouri et al., 2014; Navidian et al., 2012b; Sharif et al., 2012). Most participants mentioned difficulties related to insurance, availability of healthcare services, and dissatisfaction with hospital services, which reveals that healthcare and governmental authorities have to pay more attention to these aspects and should allocate more and appropriate resources for resolving these problems.

5.3. The quantitative phase

In this study, for the first time, a new instrument was developed and validated among an Iranian population to assess the impact of caregiving on caregivers of individuals with schizophrenia and affective disorders.

The questionnaire was based on prior questionnaires and the qualitative interviews with caregivers and point of views of expert panel and ensured its face and content validity. Because of discrepancies between relevant persons and expert panel, content of QoL measures should be derived from these people's point of views (Slevin, Plant, Lynch, Drinkwater, & Gregory, 1988).

Correlations between WHO QoL-BREF and SAC-QoL show that some dimension scores such as emotional burden, latent worry, financial burden and relationships with family and wider family are approximately similar, with medium or high correlations; but some dimensions such as dealing with patient's symptoms and relationship with therapeutic team indicated specific burdens of caregivers of patients with schizophrenia and affective disorders. In concordance with other studies about QoL of caregivers of chronic patients, it emerges that both relationships with healthcare system and coping with patients are the main specific dimensions in such instruments (Aghili et al., 2013; Minaya et al., 2012).

As the results show, the psychometric properties of the questionnaire, including reliability and validity, were very good. Our instrument explained 78.45 percent of total variance which shows a good internal consistency. Internal consistency reliabilities for the seven dimensions were high (Cronbach's alpha was more than 0.70).

Our hypotheses that explored discriminant validity were confirmed. It was found that caregivers who had cared for their patient for a longer time had lower QoL except in dimensions of RTT, FB and RE_fF that showed no significant correlation. This finding is consistent with some studies (Canam & Acorn, 1999; S. Grover & Dutt, 2011) that found that longer duration of caregiving is equal to lower QoL. This may be due to both being challenged with the patient´s symptoms for a long time which results in frustration, helplessness and other emotional burdens and receiving less professional or social support. The results show a negative relationship between QoL and caregiver's age except in RTT, RF and RE_fF that showed no significant correlation. This result is in contrast with previous studies which declared that older caregivers perceive less burden (Gutiérrez-Maldonado, Caqueo-Urízar, & Kavanagh, 2005; Richieri et al., 2011). One reason is that in the present study there is a positive relationship between age and caregiving duration. Thus, older caregivers tolerated more burdens because of having patient with severe symptoms and seeing less improvement, having long time responsibility and lacking enough support through family or government, as the most important coping strategies.

There is no difference between females and males in terms of QoL in any dimension that is consistent with some previous studies (Bengtsson-Tops & Hansson, 1999; Dimitriou, Anthony, & Dyson, 2009) and is in contrast with some others (Caqueo-Urízar et al., 2009; Narvaez, Twamley, McKibbin, Heaton, & Patterson, 2008). Because motherhood is a less frequent kinship type in the sample of this study, it is not surprising to find no difference between males and females in terms of QoL. Mothers are generally the primary caregivers and they experience the greatest burden because they feel more responsibility and commitment for most aspects of the patient´s daily care.

As expected, within the dimensions of DPS and FB, caregivers with higher education had higher QoL than those with lower education. Most studies indicated that educated caregivers have enough information about illness and it helps them to adopt better strategies to cope with patient's symptoms; also, it is not surprising that higher education is equal to lower financial burden (Alshowkan et al., 2012; Cardoso et al., 2005; Caron, Mercier, Diaz, & Martin, 2005). There is an interesting finding which shows that educated caregivers have lower QoL in dimension of RF and RE_fF. According to the Scheffe post hoc analysis it is more related to help and support by family and friends rather than being understood by them. One explanation is that family and friends do not pay enough attention to educated caregivers because of better financial conditions while they need some other types of help and support. This problem is also true for caregivers who live in rural areas; despite having both better financial conditions because of recent help and support by government and lower costs of living, and less expectation in comparison with city dwellers, they did not receive enough help and support by their family. Other explanation may be that educated caregivers and those who live in rural areas less frequently ask their family and friends for help.

Type of illness was significantly associated with QoL. Our results showed that caregivers of patients with MDD had higher QoL than caregivers of individuals with schizophrenia and BMD which is concordance with previous studies (Narasipuram & Kasimahanti, 2012; Zendjidjian et al., 2012). One explanation is that caregivers who have patients with schizophrenia or BMD experience more strain about handling bizarre and disturbing behaviors and managing fluctuating emotions.

5.4. The qualitative supplementary phase

To the best of our knowledge, the current study is the first one in Iran that explored the effect of mental illnesses on caregivers in a qualitative manner. The results of quantitative phase of the study manifested some of the main burdens that influence QoL of caregivers. Findings in the supplementary qualitative phase of the current study showed that *constantly latent worries* is the core concept or core category of caregiving experience because during the caregiving experience it was a ubiquitous category which the caregivers tried to overcome by using a variety of strategies. *Family-centered worries* focus on worries about patient and his/her illness as well as worries about relationships inside family system, between patient and other family members. Most caregivers were worried about conflicts between the patient and other family members, effect of illness on other family members or on the caregiver, probability of improvement, effectiveness of medicine and its side effects, probability of self-subsistence and financial support of the patient, life independency, unpredictable happening or behavior by the patient and about who may take care of the patient in the absence of the current caregiver. Most of the aforementioned worries stem from unpredictability of the illness, lack of knowledge about illness and its outcomes and pessimistic beliefs about the ability of patients to take care of themselves in the future life. Many studies in this scope alluded to different kinds of concerns or worries that the caregivers' experience. These studies are in accordance with our findings (McAuliffe et al., 2014; Van Der Voort et al., 2009; von Kardorff et al., 2016).

Furthermore, caregivers who live with more family members in the same place have some worries about the effect of patient on other family members (especially other children) as well as forming some conflicts between them. That is one of the reasons

which restricts some caregivers' ability of coping with patients. Our finding is consistent with the study that showed single caregivers had higher quality of life than others (Lua & Bakar, 2011) while some studies indicated that single caregivers experience more tension (Kate, Grover, Kulhara, & Nehra, 2013). An explanation for this issue is that married caregivers who have children are more worried about the impact of illness on their children, especially while the spouse cannot manage relationships with the patient and it resulted in some conflicts between the patient and other family members. When other family members, such as spouse and children, have a supportive or invigorative role instead of a debilitative interaction, the caregiver can cope with the patient much better.

Society-centered worry, identified in this study, was a sub-category of *constantly latent worries*. One of its most important sub-categories is *stigma*. Our findings show that stigma is one of the main concerns of caregivers. Many studies illustrate that all forms of stigma, either related to the illness and hospitalization or courtesy stigma, can prevent families from seeking social support as well as early and sufficient treatment for the patient (Bauer et al., 2011; Sandeep Grover et al., 2012; von Kardorff et al., 2016).

Other sub-categories of *society-centered worries* are *governmental inadequacy and defective social relations*. It included a variety of concerns such as lacking social support as well as difficulties related to the provision of medicine, cost of therapeutic system, insufficient insurance coverage, lack of supportive policies especially professional support, difficulties related to distribution of welfare and therapeutic facilities and transportation difficulties. In line with this study, some studies indicated that caregivers did not have any professional or governmental support or there is a lack of enough and continuous support by the social or

governmental organizations for the caregivers (Radfar, Ahmadi, & Fallahi Khoshknab, 2014; Shamsaei et al., 2010; Van Der Voort et al., 2009; von Kardorff et al., 2016). Social and governmental support can reduce the burden to be undergone and it should also promote successful coping.

The findings of quantitative phase indicated that caregivers suffer from different types of emotional burdens such as feelings of exhaustion, sadness, loneliness, hopelessness, helplessness and loss of energy. The results of qualitative phase showed that these emotional burdens originate from both family-centered and society-centered worries in addition to adopting inefficient coping strategies. Because of worries about stigma, most caregivers avoid asking help and support by relatives or government and consequently they feel exhausted, lonely, run out of energy and so on. Conversely, they try to convince the patient to behave in a normal way using some inefficient strategies like reproaching, advising and warning because they think it is the patient who is behaving in such a manner and it is not the disorder causing the behavior. It is true especially in the initial phase of the illness and also throughout the illness trajectory for the caregivers with lower education. The results of a qualitative study based on grounded theory method showed that spouses of patients with bipolar disorder experienced feelings like loneliness, exhaustion, helplessness and so on because they could not make a balance between self-effacement and self-fulfillment and social support such as practical help or understanding from family or friends was either too weak or completely absent. Thus, the exhaustion and loneliness became unbearable by the caregivers. The authors explain that lack of understanding and existence of social stigma still surround mental disorders in society today and presumably contribute to the absence of support which was experienced by the spouses of individuals with a bipolar disorder (Van Der Voort et al., 2009).

One of the most striking findings of the current study was the coping strategies that caregivers adopt in different situations of their caregiving experience. It is one of the main findings of the supplementary qualitative phase in comparison with the quantitative phase. These coping strategies are here categorized as: *patient's symptom management* and *stigma management*.

One of the main strategies that caregivers applied to avoid stigma was *concealment*. Some caregivers, especially those who had patients with less severe symptoms, preferred to conceal the problem or avoid from accompanying their patient in the social situations. Our findings were consistent with other studies. (Link & Phelan, 2001; Penn et al., 1994; von Kardorff et al., 2016).

According to some studies, *social presentation or involvement* is one of the adaptive coping strategies that helps the families to decrease their worries, especially worries regarding society and stigmatization (Sandeep Grover & Pradyumna, 2015).

The results of the present study indicated that some other strategies such as *self-justifying* and *informing* and *expressing family fame* are brought up predominantly after disclosure. Caregivers resort to these strategies to fade the impact of stigma on the patient. Self-justifying takes place while the caregivers want to decide between priorities of treatment or stigmatization and they justify themselves that the cure is the first priority despite the stigmatization. This concurred with some studies which asserted that active behavioral coping styles such as talking with others and active cognitive styles like positive reassessment or finding inner strength may have a primary role in coping with a mental illness (Boschi et al., 2000; Kartalova-O'Doherty & Doherty, 2008).

Findings of the present study show that *self-control expectation* is one of the sub-categories of *patient's symptom management.* It consists of some strategies such as warning, notifying, advising and reproaching the patients by caregivers because they expect the patients to behave in a normal way, especially at the beginning of the illness. Results of a grounded theory study on the caregivers of patients with bipolar disorder indicated that initially, caregivers tried to understand the behavior of the patient and wondered if it was the individual himself/herself who was behaving in such a manner or if it was the disorder causing the behavior (Van Der Voort et al., 2009). The current study shows that before such an appraisal, caregivers assumed that patients are able to control their annoying behaviors.

Attributional action is another strategy that caregivers use. It reflects some assumptions of the caregivers about the cause of problems and consequently, their actions in order to remove the attributed cause of illness. Finding of this study was consistent with some studies which indicated that some caregivers resort to some coping strategies such as prayer for good times, hope for miracles and attempt to rectify tense atmosphere and external stressors (Kartalova-O'Doherty & Doherty, 2008; Nehra, Chakrabarti, Kulhara, & Sharma, 2005). As there is a shortage of studies regarding such strategies, there is a need for further studies to explore specific aspects of relevant coping strategies.

Increasing awareness is another strategy that caregivers apply to cope with the patient's symptoms before *seeking professional help*. It included some strategies like studying, reading and counseling with some family members and people with the same problem. Many studies alluded to these strategies either implicitly or explicitly (Jönsson et al., 2011; McAuliffe et al., 2014; Mizuno, Takataya, Kamizawa, Sakai, & Yamazaki, 2013) but they lack a trajectory of coping strategies whereas our findings

suppose a priority in coping strategies to which the caregivers resort. Accordingly, *self-control expectation*, *attributional actions* and *increasing awareness* are initial strategies which caregivers use. These strategies are more related to *concealment* as one of the sub-categories of *stigma management* than the other sub-categories of *patient's symptom management.*

Some other sub-categories of *patient's symptom management* were *seeking professional support, entrusted support and periodic support.* A lot of studies showed that seeking professional, social and practical supports were the most frequent strategies that the caregivers applied. Although, in contrast with this study, they did not mention entrusted and periodic support, seeking help and support was seen in various forms such as consulting with doctors and/or extended family and friends, sharing difficulties, doing things with relatives, seeking advice from relatives, sharing concerns with friends, sharing problems with neighbors and seeking help from them (Sandeep Grover & Pradyumna, 2015; E. D. Johnson, 2000; Nehra et al., 2005; Tan et al., 2012; Van Der Voort et al., 2009).

Here, the results showed that some participants could cope with their situation better. In fact they were hopeful for both a better future and for the favor of God. A qualitative study reported some themes such as hoping for a better future, developing faith in God and participating in religious practices as the main coping strategies among caregivers of patients with schizophrenia and bipolar disorders (Ganguly et al., 2010). Also, there are some other studies in agreement with our findings (Mizuno et al., 2013; Tan et al., 2012).

The literature on the role of socio-demographic factors on the burden and QoL of caregivers shows conflicting results. Most studies indicated that caregivers who had

limited financial resources, older age, higher duration of caregiving and parent or child kinship had lower QoL. This is in line with findings of the current study in both quantitative and qualitative phases (Fan & Chen, 2009; Johansson et al., 2015; Knock et al., 2011; Lua & Bakar, 2011; Margetic et al., 2013).

It is suggested through the results of this study that caregivers who had parent or child kinship and do not live with other family members can cope with the patient better. The studies that investigated the role of these socio-demographic variables on the QoL are rare. There are only some studies that show parent and child kinship is associated with more worries (Kate, Grover, Kulhara, & Nehra, 2014; Margetic et al., 2013). Although some studies demonstrated that the parent and child kinship is associated with more worries because of more emotional engagement and attachment as well as worries about feeling of personal responsibility for the illness and worries about the future, it is not surprising that parents can cope with the patient better because they were more hopeful about a better future than others. In addition, compared with other types of kinship, parents and children feel much more compassionate to each other. It is in agreement with the results of a qualitative study which showed that developing compassion in caregiving is one of the primary coping strategies (Ganguly et al., 2010).

5.5. Limitations

5.5.1. Limitations of the exploratory phase

The exploratory phase of the current study has some limitations. It included only caregivers of inpatients, who may be more burdened than caregivers of outpatients. Also, they had been interviewed in a special moment of the life-cycle because they were in the state of an acute crisis. In addition, because the results of this study are based on a small sample size, the generalizability of the findings is limited. Further studies with larger sample sizes that include caregivers of both inpatients and outpatients in different cultures and social networks can provide more specific information about challenges of caring for a mentally-ill patient.

5.5.2. Limitations of the quantitative phase

Lack of information about the clinical severity of mental illnesses was one of the limitations of this study because it could be useful in the analysis of construct validity. In addition, this instrument was provided according to the main burdens of Iranian people which affect their quality of life. Thus, further studies are needed to investigate validity and reliability of this instrument in different cultural contexts with a larger sample size. Also, reproducibility and sensitivity to change should be explored in ongoing researches.

5.5.3. Limitations of the supplementary phase

It was difficult to identify some special participants of the quantitative phase for the interview; thus strategy to gather qualitative data was changed according to some main socio-demographic variables such as education, income, and profession. It is not possible to determine whether the sample delegates special participants of

quantitative phase or not. Nevertheless, it was tried to observe the maximum and minimum variations and contrasts among participants, in agreement with theoretical sampling principles.

5.6. Conclusion

Caring daily for a person with a mental illness is very burdensome in various fields of life. It has an impact on caregivers' well-being and quality of life and is often accompanied by restrictions in everyday routines and social relationships. Although there were some differences between caregivers of patients with schizophrenia and those with affective disorders in terms of the rank and priority of the reported burden, the pattern of burden among all caregivers was approximately identical; thus, authorities should provide adequate financial, educational, and psychosocial support for caregivers of patients with mental illness. Moreover, the authorities should afford instructive programs and information about the nature of mental disorders to reduce the impact of stigma and discrimination. Also, there is a need for ongoing research to develop adequate forms of support for families with mentally ill relatives that are tailored to the specific conditions of the caregivers' respective countries.

The findings of the current study point to the need for solutions to reduce the burdens of informal caregivers of the mentally ill. With respect to the limited resources in caregiving families and the necessity for reducing caregivers' burden, our results suggest some areas where the healthcare system can be changed, as well as point the way toward better ways to support caregivers.

The SAC-QoL revealed acceptable psychometric properties. Thus, it can provide valid and reliable measures of QoL of caregivers of individuals with schizophrenia and affective disorders. Moreover, it would be useful for clinicians and authorities to estimate the need for assistance of this specific group of caregivers, be it personal counseling, financial support or community-based assistance. Furthermore, estimating caregivers' quality of life is beneficial for preventive strategies, as caregivers are the primary actors of health care for their ill relatives over a long period of time, sometimes lifelong.

The supplementary qualitative phase illustrated that caregivers experience a heavy burden which is characterized by a core concept named "constantly latent worries". It includes a variety of concerns and burdens which are mentioned in both quantitative and qualitative phases. Concerning coping strategies, caregivers attempted to manage stigma and patient's symptoms either using an adaptive or maladaptive strategy. The findings of the current study suggest the need for different kinds of support including both supports provided by family and acquaintances, such as entrusted or periodic support, and governmental or welfare support, such as providing adequate therapeutic and welfare system as well as educational and financial facilities, so that caregivers can cope with the patient and society much better and their tendency to leave patients in an institutional take care system would decrease.

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Appendices

Appendix A: WHOQoL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5

13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5

23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

Appendix B: SAC-QoL

Please answer to the following questions according to your feelings or experience during the last 12 months.

Items	Dimensions
1) Have you felt sad/depressed?	
2) Have you felt exhausted?	EB
3) Have you felt that you lack energy?	
4) Have you felt helpless?	
5) Have you felt hopeless?	
6) Have you been able to understand your patient's behavior?	
7) Have you been able to manage bizarre and disruptive behaviors of your patient?	DPS
8) Have you had enough information about illness and process of treatment?	
9) Have you been understood by doctors and nurses?	
10) Have you been helped/supported by doctors and nurses?	RTT
11) Have you been satisfied with the information given by doctors and nurses?	
12) Have you been understood by your family?	RF
13) Have you been helped/supported by your family?	
14) Have you had financial difficulties in treating your family member's illness?	
15) Have you had housing difficulties?	FB
16) Have you had transportation difficulties?	
17) Have you been understood by your extended family and friends?	$RE_f F$
18) Have you been helped/supported by your extended family and friends?	
19) Are you worried about the possibility of leaving your patient independently without daily family support?	
20) Are you worried about constant financial support for the living of your patient?	LW
21) Are you worried about who should be in charge of your patient if you would no longer be able to support him/her?	

EB: emotional burden (5items); DPS: dealing with patient's symptoms (3 items); RTT: relationships with therapeutic team (3 items); RF: relationships with family (2 items); FB: financial burden (3 items); $RE_f F$: relationships with extended family and friends (2 items); LW: latent worry (3 items).

Appendix C: Consent form of qualitative phase

Hereby, I as the participant number----- confirm that I received complete information about the research project regarding the quality of life of family caregivers of mental illnesses and understand the intent of the study. I participate in this study voluntarily and satisfactorily. Meanwhile, I permit the researcher to record my voice owing to the confidential basics and ethical considerations of research. I agree to take part in this study deliberately and I am free to withdraw at any time without giving any reason.

Signature

Date

Appendix D: Consent form of quantitative phase

Dear participant,

Hereby, I inform you that this questionnaire developed in order to assess the quality of life of family caregivers of patients with mental illnesses. We keep the information that you will mention in this questionnaire anonymously and confidentially. Meanwhile, the whole data were analyzed collectively. If you intend to participate in this study, please answer the following questions. In advance, the researcher appreciates you because of your collaboration and time in the study.

Signature

Date

Appendix E: Interview guide

Introduction

- Beginning interview friendly greeting and explanations.
- Explain the participant the purpose of the interview and advantages of the finding of the study, and encourage them to answer questions.
- Remind participant that the interview will be tape-recorded and the information they give are confidential.
- Giving confidence the participant that he/she is free to withdraw from the study at any time without giving any reason.

Narrative generating questions

- Would you please tell me how and when problems with your ill family member started?
- Can you tell me about your story?
- Would you please tell me from the beginning up to now?

Topics (main questions)

- Would you please tell me about your experience with the psychiatric system, doctors, and nurses?
- What are the main troubles in your everyday life? Can you give examples?
- Have your relations within family changed?
- Have your relations with the patient changed?
- Have your relations with extended family and friends changed?
- Do you have any financial problems associated with your relative's condition? What is the cause of these?
- Can you tell me how living with someone with your relative’s condition makes you feel?
- Have you received any support from welfare organizations? If so, what were those?

- What effect does your relative's condition have on your day to day activities?

- Did you have any problem related to the hospitalization of your patient?

- Dou you have any worry about stigma? If so, what did you do?

Closure

- what do you think about the future
- Is there anything else you can think of that you have not told me?
- Is there anything else you would like to discuss?

Thank you for your time.

Appendix F: Original questionnaire

1) Have you felt sad/depressed?
2) Have you felt exhausted?
3) Have you felt that you lack energy?
4) Have you been tired/worn-out?
5) Have you felt anxious?
6) Have you had to give up doing things that you were keen to do?
7) Have you had to reduce the amount of time devoted to your leisure activities (outings, shopping and so on)?
8) Have you had the feeling that you did not devote enough time to the rest of your family?
9) Have you felt you were not free?
10) Have you felt you led a day to day life?
11) Have you been understood by your spouse?
12) Have you been helped/supported by your spouse?
13) Have you been understood by doctors and nurses?
14) Have you been helped/supported by doctors and nurses?
15) Have you been satisfied with the information given by doctors and nurses?
16) Have you been understood by your family?
17) Have you been helped/supported by your family?
18) Have you been understood by your friends?
19) Have you been helped/supported by your friends?
20) Have you encountered difficulties because of your patient's illness when referring to governmental organizations?
21) Have you had financial difficulties in treating your family member's illness?
22) Have you had material difficulties? (housing, transportation, …)

23) Have you been able to understand your patient's behavior?
24) Have you been able to manage bizarre and disruptive behaviors of your patient?
25) Have you felt helpless?
26) Have you felt hopeless?
27) Have you felt lost?
28) Have you been worried about your patient's future and possibility of self-subsistence of your patient?
29) Have you been worried about your other family members?
30) Have you been worried about yourself?
31) Have you had enough information about the illness and process of treatment?
32) Have you felt embarrassed because of your patient’s behavior?
33) Have you felt angry because of your patient’s behavior?
34) Have you felt worried or sad because of stigma?
35) Have you been understood by your acquaintances?
36) Have you been helped/supported by your acquaintances?
37) Have you been worried about referring to the psychiatric hospital or psychiatrist?
38) Has your routine been interrupted?
39) Have you had some conflicts with your family or acquaintances because of your patient's illness?
40) Have you encountered difficulties in compliance and taking medicine by the patient?
41) Have you had to reduce contacts with your extended family and friends?
42) Have you felt that you have been limited for doing routine?
43) Have you felt guilty?
44) Have you had difficulties in division labor and responsibility in routine?

45) Have you been worried about the impact of patient’s illness on your family members?
46) Have you been worried about the impact of patient’s illness on yourself?
47) Have you been worried about your patient commits suicide?
48) Have you had physical problems or pain?
49) Have you been satisfied with availability of health services?
50) Have you been satisfied with your insurance?
51) Have you felt that you had a monotonous and boring life?
52) Have you been worried about your patient's relapse and re-hospitalization?
53) Have you had the feeling that you did not devote enough time to the rest of your family?
54) Have you had the feeling that you did not devote enough time to yourself?
55) Have you been satisfied with your sex life?
56) Have you felt pleasurable or vital?
57) Have you had to donate the caregiving role to the others?
58) Have you been satisfied with the psychiatric team?
59) Have you been worried about your patient hurts you?
60) Have you been worried about your patient hurts others?
61) Have you been worried about your patient hurts oneself?
62) Have you helped, supported by governmental organizations?
63) Have you had difficulties about providing medicine?
64) Have you had the feeling that you are responsible for everything at home?
65) Have you been satisfied with your sleep?
66) Have you had difficulty in making professional or personal plans?
67) Have you felt frustrated?